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ABSTRACT

This document presents summaries of a variety of resources concerned with the inclusion of people with developmental disabilities in faith communities. Each listing usually provides bibliographic information, source and price information, and a summary or description. Following an introductory essay, the first section provides summaries of 43 articles, books, curricula, and videos. The next section describes three resources for L'Arche, an international federation of intentional and inclusive faith communities. The next three sections describe six newsletters, five mission and pastoral statements, and 16 organizations. Attached are reprints of the following articles: "A Rosh Hashanah Birthday" (W. C. Gaventa); "How the Religious Community Can Support Transition to Adulthood: A Parent's Perspective" (B. Hornstein); "Disability for the Religious" (P. J. Majik); "Frayed at the Edges: The Intertwined Threads of Life and Disability" (M. J. Owen); "The Wisdom of Human Vulnerability--Disability: The Tie Which Binds" (M. J. Owen); " Who Causes the Blind To See'? Disability and Quality of Religious Life" (A. Rose); and "The Masks of God" (A. Sobolewska). (DB)

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FAITH COMMUNITIES AND INCLUSION OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

by
Mair Hall and Philip Lambert

April 1998

Center on Human Policy
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Acknowledgments

We would like to acknowledge the following persons for their help in the preparation of this package. We thank Mary Jane Owens, who is the executive director of the National Catholic Office for Persons with Disabilities and co-editor of the NCPD National Update newsletter; Tom Cunningham, who is director of the Ministry with Persons with Disabilities Catholic Diocese of Syracuse, NY; Bill Gaventa co-editor of the NJ Coalition for Inclusive Ministries newsletter; and Becca Hornstein, who is Executive Director at the Council for Jews with Special Needs, Inc., all for helping gather the resources we included in this package. Finally, we thank Rachael Zubal at the Center on Human Policy for helping us gather resources and especially for keeping an eye out for resources that had gotten buried in our library or that had newly arrived.

Introduction

People with disabilities have a long relationship with faith communities. Take for example the following passage from the book of Deuteronomy on people who are blind: "And you shall grope at noonday as the blind gropes in the darkness" (28:29). How do we interpret this passage? Jewish and Christian traditions tell a very similar story to interpret it. The Jewish telling of the story goes like this:

> *Now what difference does it make to a blind man whether it is dark or light? I didn't find out until the following incident occurred. I was walking on a pitch black night when I saw a blind man walking in the road with a torch in his hand. I said to him, "My son, why are you carrying a torch?" He replied, "As long as I have this torch in my hand, people see me and save me from the hole and the thorns and briars."*
>
> (Megillah 24b in Astor, 1985, p. 76-77)

People who are blind "grope," not because of their blindness, but because of their community's blindness toward them–that is, their community's lack of support to them. To take this interpretation one step further, using an example from the Christian tradition, the blind person is said to carry the torch to light the way for others who might also be out in the pitch black. Both of these interpretations show that including people with disabilities in faith communities is deeply rooted in the philosophies of both of these religious traditions.

Not withstanding the exclusion and rejection that members of faith communities have practiced toward people with disabilities, throughout history there have always been members of these communities who loved, supported, and respected their fellow human beings with disabilities. They did this mostly through charity work toward people with disabilities: caring, feeding, housing, and protecting them. Take, for example, the Catholic and Protestant Bishops in Germany during the time of Hitler who carried out letter-writing initiatives, to the risk of their own lives, against Hitler's murder campaign against German people with disabilities. One of our favorite stories from this time goes as follows:

> *In the little village of Absberg, in southern Germany there was the Abbey of Ottilienheim. The Abbey which was across from the parish of St. George had been home for people with disabilities for many, many years. The nuns of the Abbey cared for their residents, most of whom were from the town itself, members of the local Catholic families of farmers and trades persons.*
>
> *One day in the fall of 1940 a gray bus came into the courtyard of the Abbey. While the villagers watched, a number of the residents of the Abbey were put on the bus and taken away. Never seen again, the villagers and the nuns were told by the local constable that the residents all died of influenza. However, the villagers did not believe this story. These were members of their own families, and known to most of the villagers. In this small Catholic village, the nuns and the people with disabilities had always been a part of St. George's services.*
>
> *In the winter of the following year, the Mother Superior was informed by the Nazi's that another bus was coming. She was told not to tell anyone. However, Mother was very upset by this news and told the local priest. The next morning, before sunrise, the nuns woke their residents and despite the risk, took them to mass for a special service at St. George's. After mass, the priest told the*

> *residents that 75 of them were about the be taken away on one of the gray buses. The residents knew what this meant.*
>
> *When the bus came later that day, the entire village followed the bus to the Abbey, in protest. The residents refused to get on the buses and many of the nuns and residents hung to each other. It was no use, the Nazis used force to drag them apart and onto the buses ...*
>
> (retold from Gallager, 1995)

Today, stories such as the these two have inspired members of faith communities to work with people with disabilities to develop inclusive faith communities.

This information package includes examples and resources of how these people think about, and work toward, building faith communities where all people are welcome. The package is divided into four sections. The first section contains articles, books, curricula, and videos that discuss both philosophical and pragmatic ways in which faith communities and their congregents, with and without disabilities, can work together for the building of inclusive faith communities. Within this section we have included a subsection on writings about L'Arche. We separated out these writings because L'Arche faith communities are a unique example of full-time, life-sharing, intentional religious participation. They are not meant to represent the only way by which people with disabilities can be included in faith communities. The second section lists newsletters, the majority of which are free-of-charge. In the third section we have listed several mission and pastoral statements. These statements lay out how different faith communities support and work for the inclusion of people with disabilities. For example, Rabbi Schneerson of the Lubavitch Hassidic Jewish community makes it very clear that Jewish children with disabilities have the full right to be included in Jewish life. Similarly, the pastoral statement of the U.S. Catholic bishops makes its clear that Catholics with disabilities have every right to be included in all aspects of church life. The fourth section lists organizations who work and publish information on how to make faith communities inclusive. In the final section we have included several reprints of articles and mission and pastoral statements that we feel best detail the meaningfulness, the complexities, and the challenges of working toward this inclusion.

We realize that this is not a comprehensive package, and we are continually working to find new resources especially from those faith communities which admittedly are underrecognized here. There is a dearth of information available on this topic. Some of this information recognizes that people with disabilities have spiritual lives and needs, yet addresses this life and need within the contexts of separate, "special" services and programs. What we are interested in is faith communities that are thinking about the complexities of, and working toward, including people with disabilities within mainstream faith settings and practice. For this reason, we chose resources that we feel best represent this inclusive philosophy.

References

Astor, C. (1985). Who makes people different?: Jewish perspectives on the disabled. New York: United Synagogues of America.

Gallager, H. G. (1995). By trust betrayed: Patients, physicians, and the license to kill in the Third Reich (Rev. ed.). Arlington, VA: Vadamere Press.

Articles, Books, Curricula, & Videos

TITLE: We don't have any here: Planning for ministries with people with disabilities in our communities

AUTHOR: Anderson, W., Gould, T. & Paul, J.

PUBLICATION INFORMATION: 1986

Discipleship Resources
P. O. Box 840
Nashville, TN 37202

Written by people well known for their work and writing in the disability area, specifically regarding disability concerns for the United Methodist tradition, this 42 page booklet is concerned with ministering to people with developmental and other types of disabilities. Containing 3 chapters, the first chapter looks at different types of ministries including an inclusive preschool, respite care, summer camps, young adults groups, congregational awareness about disability, congregational support and advocacy, and making group home residents part of your faith community. The second and third chapters examine the *Resurrection Preschool*, an inclusive church preschool program, and the needs and resources in the community for planning inclusion of people with disabilities in faith communities.

TITLE: "Who make the disabled different?" Jewish perspectives on the disabled

AUTHOR: Astor, C.

PUBLICATION INFORMATION: 1985

S. Garfinkel (Ed.)
United Synagogues of America
Department of Youth Activities
155 Fifth Ave.
New York, NY 10010

This book is an excellent introduction into multiple ways of understanding disability within the Jewish tradition. Astor organizes the book into several chapters which address references to disability in biblical sources, rabbinical sources, and connections to Jewish philosophies and core values. Throughout the book, the reader is challenged to question and interpret the material and relate it to issues about disability within their own community or congregation. The book offers concrete advise to help individuals and congregations become more accommodating and inclusive. It is particularly oriented to youth groups and schools and would be a valuable educational guide.

TITLE: A bill of rights for persons with mental retardation in relation to congregations

AUTHOR: Bethseda Lutheran Homes

PUBLICATION INFORMATION: 1992

Bethseda Lutheran Homes and Services, Inc.
700 Hoffmann Dr.
Watertown, WI 53094

This flyer lays out the rights of people with labels of mental retardation in relation to congregations with regard to respect, accessibility, acceptance, inclusion, service, education, compassion, understanding, advocacy, and friendship.

TITLE: Do's and don'ts: Welcoming people with disabilities

AUTHOR: Bishop, M. E.

PUBLICATION INFORMATION: 1994

CHURCH Magazine
The National Pastoral Life Center
299 Elizabeth St.
New York, NY 10012-2806
(212) 431-7825

This pamphlet is designed to give parishioners and clergy a quick first-step guide as to what to do, and not to do, in welcoming and worshipping with parishioners with disabilities. Author Marilyn Bishop, who is involved with Disability Ministry at the University of Dayton, Ohio, covers the do's and don'ts in welcoming people with the impairments of: visual, physical or mobility, speech, comprehension, deafness and hearing, and mental illness impairments. She also provides very practical tips on language that is or is not welcoming of people with disabilities.

TITLE: Dimensions of faith and congregational ministries with persons with developmental disabilities and their families–Updated and expanded

AUTHORS: Building Community Supports Project, University Affiliated Program of NJ & The Religion Division of the AAMR

PUBLICATION INFORMATION: 1996

Building Community Supports Project, University Affiliated
Program of NJ & The Religion Division of the AAMR
31 Alexander St.
Princeton, NJ 08540
(908) 235-4408

COST: $10.00

Compiled by the religion division of the AAMR, this excellent bibliography and address listing was produced for clergy, lay persons, families, and service providers, to help them in the inclusion of people with disabilities in faith communities. Sections covered are: Worship and Sacraments: The Arts: Architectural and Attitudinal Accessibility: Scriptural, Theological, and Ethical Issues: Religious Education Guides and Curricula: Jewish Resources and Organizations: and National Faith Group Resource and Consulting Offices.

TITLE: Dimensions of faith and congregational ministries with persons with developmental disabilities and their families–1998 edition

AUTHOR: Community Building Partners & The Religion Division AAMR

PUBLICATION INFORMATION: 1998

Community Building Partners
c/o 45 Knightsbridge Rd.
PO Box 6810
Piscataway, NJ 08855-6810
(732) 235-4078
TDD: (732) 235-4407

An updated and expanded edition of the 1996 edition, *Dimensions of Faith* is a bibliography and address listing of resources for clergy, laypersons, families, and service providers. Included this time, among other areas of interest, is information on worship and sacraments, music and arts, architectural accessibility, outreach, ethics and theology, pastoral care around death, grieving, and sexuality, children, for parents and families for persons with disabilities, Jewish resources, audio visual resources, journal, articles, and magazines, and the addresses of national faith organizations.

TITLE: Sharing the journey: Active reflections on the Church's presence with mentally retarded persons

AUTHOR: Cook, E.

PUBLICATION INFORMATION: 1986

W. C. Brown Co. Publishers
now distributed through:
National Catholic Office for Persons with Disabilities
P. O. Box 29113
Washington, DC 20017
(202) 529-2933

This book is a collection of 14 articles written by members of the National Apostolate for Persons with Mental Retardation (NAPMR). Articles discuss: roles of the church, parent advocacy, sexuality, residential services, the medical profession, education, and finances. Two chapters that are key for those interested in the inclusion of people with disabilities in faith communities are "A Church's Presence to Families with Members Who are Mentally Retarded" and "The Role of the Church in Providing Comprehensive Services and Ministries for Families."

TITLE: The Disability Rag resource on religion and disability

AUTHOR: The Disability Rag

PUBLICATION INFORMATION: 1993 (Sept/Oct)

Disability Rag,
The Disability Rag & ReSource
P. O. Box 145
Louisville, KY 40201

A special issue of this disability rights magazine dedicated to religion and disability, this issue is excellent. We can read of discussions on the Pope, the Bible and disabilities, a world view on religion and disability, religion and the ADA, faith healing, and communion to name a few topics. Also included, is a reading list and some lovely poetry.

TITLE: Open hearts: A youth ministry resource on inclusivity

AUTHOR: Division for Congregational Ministries

PUBLICATION INFORMATION: 1992

Division for Congregational Ministries
Evangelical Lutheran Church in America
Distribution Services
426 South 5th St., Box 1209
Minneapolis, MN 55440
1-800-328-4648

Although this publication does not focus on disability alone–it also looks at gender, age, and culture–it does look at issues of inclusion of people with developmental disabilities in faith communities.

TITLE: The disabled God: Toward a liberation theology of disability

AUTHOR: Eiesland, N.

PUBLICATION INFORMATION: 1997

Abingdon Press
201 Eight Ave. South
P. O. Box 801
Nashville, TN 37202-0801
1-800-251-3320

Through this book Eiesland, who became disabled as a child when she had polio, helps the reader to see how the "hidden history" of conventional bodies living ordinary lives with grace and dignity, disgust and illusion, can make for both a theological and pastoral contribution. Arguing for a liberation theology, she calls on us to move away from our defining of people with disabilities as people who need to adjust to a minority group that is subject to social stigmatization. While her examples tend to be based on the experiences of people with physical disabilities, what she has to say is also insightful for those working to include people with developmental disabilities in faith communities.

TITLE: Opening our community to Jews with disabilities

AUTHORS: Elbaum, E., Cohen, E., Thomas, N. & Steer, M.

PUBLICATION INFORMATION: 1993

Australia Disability Review, 1(93), 42-47

This article was a collaboration, written by a group of community advocates consisting of self advocates with disabilities, parents, and other community members. It outlines their collective effort to raise community awareness about disability issues within the Jewish community and empower those involved in the process. Throughout, they emphasize a strong sense of inclusion to create a diverse but close community. The article details the variety of innovative strategies they continually need to employ to reach unreceptive audiences.

TITLE: What it's like to be me

AUTHOR: Exley, H. (Ed.)

PUBLICATION INFORMATION:

Friendship Press
P. O. Box 37844
Cincinnati, OH 45222-0844
1-800-889-5733

COST: $10.95 (plus shipping)

Written and illustrated entirely by children with disabilities, *What It's Like to Be Me*, talks about what it is like to be a child with a disability who wishes to participate in life without being subjected to pity or prejudice. What the children say in this book will be helpful for those who wish to include children with disabilities in their faith communities. For example, one of the child authors writes, "apart from the annoying factor of breaking things, one of the worst things for me is being treated like a baby." Friendship Press has been publishing Christian books on religion and faith since 1902. A free catalogue is available by calling their 1-800 number.

TITLE: Health and medicine in the Jewish tradition

AUTHOR: Feldman, D. M.

PUBLICATION INFORMATION: 1986

In Mental as well as physical health (pp. 49-53). New York: Crossroad Publishers.

Crossroad Publishers
370 Lexington Ave
New York, NY 10017
(212) 532-3650

This chapter addresses many of the same themes which were discussed in the articles by Shapiro and Wertlieb. However, Feldman relates them to ideas about health and illness, mind and body within the Jewish tradition. The reader can, therefore, connect many issues pertaining to disability to other Jewish principles.

TITLE: By trust betrayed: Patients, physicians, and the license to kill in the Third Reich (Rev. ed.)

AUTHOR: Gallager, H. G.

PUBLICATION INFORMATION: 1995

Vadamere Press
P. O. Box 5243
Arlington, VA 22205

In *By trust betrayed*, Gallager looks at the Nazi euthanasia program that led to the murder of more than 200,000 people with disabilities. However, not all people in Nazi Germany approved of this supposed mercy killing and ethnic cleansing. Rather, members of various religious communities rose to oppose Hitler's Aktion T-4 systematic program of killing people with disabilities. While this book does not focus specifically on the religious communities' opposition to Aktion T-4, it does contain several stories of practicing clergy, nuns, lay persons, parishioners, and whole villages who actively, and openly, opposed the program through letter writing campaigns, sermons from the pulpit, and trying to physically stop people with disabilities from being sent to death often at the risk of their own lives.

TITLE: A Rosh Hashanah birthday

AUTHOR: Gaventa, B.

PUBLICATION INFORMATION: 1997

The Common Thread Newsletter
c/o UCP
4638 Centre Ave.
Pittsburgh, PA 15213

In this real life account Reverend Gaventa tells of the spiritual experiences of three adults with disabilities. There is Harry, who is 75, and who asks to kiss the Torah. Then, there is Sally who is always the first one to come to a service. She cannot speak, but she can murmur her prayers. And then, there are Naomi and Mark and Bill and the Rabbi. This delightful slice reminds us that it is a lot easier to include people with disabilities in our faith communities than we often lead ourselves to believe.

TITLE: Courage to care: Seven families touched by disability

AUTHOR: Griffith Ransom, J.

PUBLICATION INFORMATION: 1994

Upper Room Books
1906 Grand Ave.
P. O. Box 189
Nashville, TN 37202
1-800-972-0433

COST: $9.95

This book tells the stories of seven families, each with a family member with a disability. These families tell how their lives were changed considerably by ordinary congregations, friends, and neighbors who cared. With regard to people with developmental disabilities, we read about the life of Jason, who has Down syndrome, Christina and Natalie, who have Rett syndrome, and Jim, who has cerebral palsy. Included also are three Appendices which: (1) offer advice on guidelines for helping, appropriate language, caring skills, do's and don't's list for persons visiting families with children with disabilities, and practical suggestions from a parents: (2) a list of print resources; and (3) a brief list of disability organizations.

TITLE: Integrating religious and secular perspectives in the design and delivery of disability services

AUTHOR: Heifetz, L. J.

PUBLICATION INFORMATION: 1987

Mental Retardation, 25(3), 127-131.

Often religious and secular services are seen as polarized, or at best, in conflict. Heifetz examines the roots of each, and the roots of the perceived tension. His conclusions are that these are not two philosophical approaches. In many ways, he believes that they are hybrids, with similar histories, based on similar principles and continually influencing each other. By opening up dialogues, Heifetz believes that we can achieve more tolerance in individual practice and choice.

TITLE: Supporting the free exercise of religion in the group home context

AUTHOR: Hoeksema, T. B.

PUBLICATION INFORMATION: 1995

Mental Retardation, 33(5), 289-294

This article describes ways in which group home employees can support people with disabilities in the active expression of faith, both inside and outside of the home, while at the same time protecting the rights of others in the home who choose not to participate in religious expression. For example, religious practices can be allowed in a group home as long as no one is coerced to participate, consider past practices of residents, such as, praying at meal time, and using natural support to meet people's religious needs.

TITLE: Jewish life cycle events: Including children with developmental disabilities

AUTHOR: Hornstein, B.

PUBLICATION INFORMATION: 1996

Disability Solutions, 1(4) 9-11.
9220 S.W. Barbur Blvd. #119-179
Portland, OR 97219-5428
(503) 244-7662
email: dsolns@teleport.com
http://www.teleport.com/~dsolns

Becca Hornstein, the Executive Director of the Council for Jews with Special Needs, recounts some personal experiences she had in helping to include individuals with disabilities in synagogue activities and rituals. She offers several strategies to help make accommodations for people with mental and physical disabilities to participate in services; but further, she believes that full inclusion of people with disabilities will change the service in positive ways.

TITLE: How religious communities can support the transition to adulthood: A parent's perspective

AUTHOR: Hornstein, B.

PUBLICATION INFORMATION: ~~1997~~

Mental Retardation, 35(6), 485-487

Using the personal experiences of herself and her son as he approached the age of 21. Hornstein reflects on how religious communities can help young adults with disabilities as they make the transition from school to adult life. She reminds us that part of growing up is about making your own mistakes and learning from them. It's also about learning how to keep yourself safe in potentially dangerous situations. That is, it is also about giving people they time *they* need to learn. Religious communities can provide support during this time of transition by providing loving environments, by challenging social discrimination against people with disabilities, and by allowing people with disabilities to advocate for themselves in youth groups, camps, and so on.

TITLE: Journal of Religion in Disability & Rehabilitation

PUBLICATION INFORMATION:

Haworth Pastoral Press
of Haworth Press, Inc.
10 Alice Street
Binghamton, NY 13904-1580
1-800-342-9678

First published in 1994, this journal publishes quarterly articles that pertain to the inclusion of people with disabilities in faith communities. Topics from past articles have included ministry to people with disabilities, parental and theologian reflections, marginalization, the deinstitutionalization of specialized ministries, spiritual responses to disability, and adaptive equipment.

TITLE: Disability for the religious

AUTHOR: Magik, P. J.

PUBLICATION INFORMATION: 1994 (Nov/Dec)

Disability Rag, 24-25.
The Disability Rag & ReSource
P. O. Box 145
Louisville, KY 40201

This article serves as a poignant reminder to non-disabled members of faith communities of the arguments they have used in the past, and in some cases still do, to exclude people with disabilities from actively participating in faith communities. Magik talks about how disabilities have been seen by the religious communities as signs of punishment and the sins of the fathers visited upon the children, tests of faith, acts of God, and in need of curing.

TITLE: A drama of love: A Christian educator's guide to creating classes where everybody belongs

AUTHORS: Mullet, J. & Snyder, P.

PUBLICATION INFORMATION: 1993

Mennonite Central Committee
Mennonite Mutual Aid
Advocacy & Education Resource Department
P. O. Box 483
Goshen, IN 46527
1-800-348-7468

COST: free to members of Mennonite congregations, $3.00 to nonmembers

Designed for religious education teachers, this booklet provides a practical step-by-step guide for including children with disabilities in inclusive religious education programs. Included are ways to use drama in inclusive classrooms. Cautions described include falling into the trap of inadvertently ascribing hero or heroine status to people with disabilities. Included also is a resource list of books, videos, films, and puppets that can be used in an inclusive religious education classroom.

TITLE: A loving justice: The moral and legal responsibilities of the U.S. Catholic church under the Americans with Disabilities Act

AUTHOR: National Catholic Office for Persons with Disabilities

PUBLICATION INFORMATION:

National Catholic Office for Persons with Disabilities (NCPD)
P.O. Box 29113
Washington, DC 20017-0113
(202) 529-2933 (v/TTY)

Dedicated to "the ten million of our brothers and sisters with disabilities," this book offers guidance for Catholic parishes and clergy as to how they can use the regulations under the ADA to make their parishes more inclusive, and serves as a reminder of the continuing obligation to work for the full participation of people with disabilities in our faith communities.

TITLE: Carrying on the crusade: Celebrating life in all its diversity

AUTHOR: National Catholic Office for Persons with Disabilities

PUBLICATION INFORMATION: 1997

NCPD
P.O. Box 29113
Washington, DC 20017-0113
(202) 529-2933 (Voice/TDD)

Also available from the Resource File, Opening Doors to People with Disabilities—Volume II, this piece advocates for the celebration of diversity in the culture of life in the face of physician-assisted suicide and selective abortion of so-called "defective" fetuses. Discussed are ways in which faith communities can work with, and in the protection of, people with disabilities against a "culture of death." All in all, a down to earth piece on how to celebrate life in all its diversity in face of those who see people with disabilities as burdensome to society.

TITLE: Opening doors to people with disabilities–Volume II–The resource file

AUTHOR: National Catholic Office for Persons with Disabilities

PUBLICATION INFORMATION: 1997

NCPD
PO Box 29113
Washington, DC 20017-0113
(202) 529-2933 (v/TTY)

This resource file is an extensive, 1,350 page encyclopedia of information on including people with disabilities in ministry. The resource file centers on the inclusion of people with assorted disabilities and includes descriptions of ways in which to include people with disabilities in religious education, ethical considerations, and family ministries. It also includes disability fact sheets and statistics, eminent Church documents, original essays and resources lists. Essay topics include: curricula, theological interpretations of disability, position statements on mercy killing, to name a few examples.

TITLE: Celebrating differences: A leader's guide

AUTHOR: Neufeldt, A. (Ed.)

PUBLICATION INFORMATION: 1984

Faith and Life Press & Mennonite Publishing House
616 Walnut Ave.
Scottdale, PA 15683
1-800-245-7894

This guide is designed for teachers and Clergy in adult Sunday school classes who wish to learn how to better respond to people with disabilities. The guide challenges us to accept and also to celebrate people with disabilities in their faith communities. Topics include: attitudinal barriers, experiences of rejection by parents and children with disabilities, education, faith development, life-planning, and quotations from people with developmental disabilities. All in all, this guide highlights the potentials of people with disabilities to understand faith.

TITLE: Open hearts, open minds, open doors

AUTHOR: Pathways Awareness Foundation

PUBLICATION INFORMATION: 1997

Pathways Awareness Foundation
123 N. Wacker Drive
Chicago, IL 60606-1700
1-800-955-2445
TDD: (312) 236-7411
http://www.archdiocese-chgo.org

COST: $21.95 (including shipping)

This video was produced from the Inclusion Conference held in Chicago that was led by the late Cardinal Bernardin and Father Henri Nouwen. In *Open hearts, open minds, open doors*, these men, who are well known within the Catholic faith community for their work toward the creation of inclusive faith communities, provide insights into and guidance for the inclusion of people with disabilities in liturgy and church life. Specific topics they discuss are affirmation, communication–sign interpretation, large print, Braille, people first language, TDD, cassettes, animation, accessibility, keeping inclusion alive, and examples of inclusive prayers and petitions. Also included are practical bulletin inserts, which can be duplicated, on how to make your faith community more inclusive.

TITLE: "Who causes the blind to see": Disability and quality of religious life

AUTHOR: Rose, A.

PUBLICATION INFORMATION: 1997

Disability & Society, 12(3), 395-405

In this article, Rose looks critically at how ancient beliefs in the Christian and Jewish traditions, and their resulting practices have often led to exclusion from churches and synagogues and societal oppression of people with disabilities. That is, although people with disabilities "often turn to religious institutions for comfort and belonging," ancient beliefs–which result in religious definitions of disability as "signs of punishment or evil incarnation," "challenges to divine perfection," "objects of pity and charity," and "incompetence and exemption from religious practice"–prevent them from being welcomed, openly, into faith communities. Rose helps the reader challenge the sources of his or her own beliefs about disability and the place of people with disabilities in churches and synagogues, to help the reader move toward the building of faith communities where "all may find fulfillment and inclusion...."

TITLE: Mental disorders: A chapter from the work of Preuss

AUTHOR: Rosner, F.

PUBLICATION INFORMATION: 1978

Journal of Psychology & Judaism, 3(2), 126-140.

This article looks at the work of Julius Preuss who wrote a classic book on Biblical and Talmudic medicine. Preuss was one of the first writers to look at scriptural writings on medicine and illness—which at the time included mental disorders—to look at how their authors described these disabilities. Rosen looks at the implications for Preuss' ideas in modern day Judaic interpretations of mental disorders.

TITLE: Who cares? Rediscovering community

AUTHOR: Schwartz, D.

PUBLICATION INFORMATION: 1997

Westview Press
Harper Collins Publishing Inc.
10 East 53rd Street
New York, NY 10022
212-207-7000
http://www.harpercollins.com/

Although this book does not relate specifically to the inclusion of people with disabilities in faith communities, it does look at the nature of communities that find humane responses to caring for and including people with disabilities. Schwartz talks about how communities can supplement social service systems to help provide richer and better lives for people with disabilities. The role of religious traditions of hospitality and care are discussed in view of how communities can be made stronger and more welcoming to all people.

TITLE: Pastoral care of the mentally disabled: Advancing care of the whole person

AUTHORS: Severino. S. K.. & Liew. R (Eds.)

PUBLICATION INFORMATION: 1994

Papers presented at the New York
Hospital-Cornell Medical Center and the
American Ass. of Pastoral Counselors
May 13. 1992

The collection of symposium papers includes topics such as. role of faith in mental healing. the role of mental health in spiritual growth. madness. mental health and the ministry. rage at God. having a parent who dies of AIDS. and mending the mind and mending the soul.

TITLE: The status of the mentally ill in Jewish law

AUTHOR: Shapiro. Y. A.

PUBLICATION INFORMATION: 1993

Medicine & Law. 12. 317-324

This is another comprehensive and valuable reference for those who wish to reflect current ideologies to religious. legal. and philosophical sources. For example. should persons labeled with mental illness (the Talmudic term *Shoteh*) be expected to perform religious responsibilities. or should they be permitted to marry? Talmudic concepts about mental illness lead to certain categorizations and decisions. Shapiro discusses the implications of these for modern practice and understanding.

TITLE: The masks of God

AUTHOR: Sobolewska. A.

PUBLICATION INFORMATION: 1997

In A. Gustavsson & E. Zakrzewska-Manterys (Eds.). Social definitions of disability (286-303). Warsaw: Wydawnictwo Zak.

This chapter is from a Swedish and Polish edited book on social definitions of disability. The author, Sobolewska, who is the mother of Cecylia, a little girl with Down syndrome, looks at different theories of disability within both the Jewish and the Christian faith traditions. She tells us what it was like to give birth to a child with a disability among "Job's friends" who hold to these different faith theories of disability; theories that associate disability with acts of a higher power, punishment, a cross to which parents never really become accustomed to, or "Christmas which lasts all year." Sobolewska then reflects on her feelings about her daughter and what she sees as her daughter's place within their faith community, saying "God does not have His own face. Every human face is the face of God" (p. 301). She suggests we stop hiding behind our own masks of fear in relation to people with disabilities, instead, looking beyond the external mask of disability to the person beneath.

TITLE: Leonard's legacy: Innovative ventures in serving Jews with disabilities

AUTHORS: Solomon, S., Howard, R., Lazerus, L., & Spraetz, W.

PUBLICATION INFORMATION: 1997

Jewish Journal of Communal Service, 181-187

This article describes several innovative agencies and projects throughout the U.S. and Canada that emphasize "choice" and "inclusion." It relates the challenges that these organizations face as they promote such initiatives as personal supports, creative living arrangements, self-determination, in respect to Jewish heritage.

TITLE: Loving justice: The ADA and the religious community

AUTHOR: Thornburgh, G.

PUBLICATION INFORMATION: 1996

National Organization on Disabilities
910 Sixteenth Street, N. W., Suite 600
Washington, DC 20006
(202) 293-5960
TDD: (202) 293-5968
http://www.nod.org

COST: $10.00 (bulk discounts available)

Loving justice is a 32 page, question-and-answer format book that aims to clarify the relationship between the Americans with Disabilities Act, other relevant disability laws, and the religious community. Both legal and moral mandates are described.

TITLE: That all may worship: An interfaith welcome to people with disabilities

AUTHOR: Thornburgh, G.

PUBLICATION INFORMATION: 1997

National Organization on Disabilities
910 Sixteenth Street, N.W., Suite 600
Washington, DC 20006
(202) 293-5960
TDD: (202) 293-5968
http://www.nod.org

COST: $10.00 (bulk discounts available)

That all may worship was designed to assist congregations, denominational groups and seminaries in welcoming people with disabilities. This award-winning 52-page handbook is now in its fifth printing, is inter-faith, and is concerned with people with all types of disabilities.

TITLE: From barriers to bridges: A community action guide for congregations and people with disabilities

AUTHOR: Thornburgh, G. & Rife, J.

PUBLICATION INFORMATION: 1996

National Organization on Disabilities
910 Sixteenth Street, N.W., Suite 600
Washington, DC 20006
(202) 293-5960
TDD: (202) 293-5968
http://www.nod.org
$10.00 (bulk discounts available)

From barriers to bridges is a 62 page community action guide for congregations with congregents with disabilities. This guide focuses on the elimination of obstacles that hinder access to a full life of faith for people with disabilities through suggestions, such as to how to foster dialogue between people with disabilities, their family members, religious leaders, and the larger community.

TITLE: Dancing with disabilities: Opening the Church to all God's children

AUTHOR: Webb-Mitchell, B.

PUBLICATION INFORMATION: 1996

United Church Press
700 Prospect Ave.
Cleveland, OH 44115-1100
1-800-654-5129
ucpress@ucc.orc
http://www.ucpress.com

COST: $15.95

Written by Presbyterian minister Webb-Mitchell, this book is about what it would be like if those with and without disabilities understood themselves to be equal parts of the Christian community. In *Dancing with disabilities*, we meet several young people with developmental disabilities who are included in their faith communities. For example, we meet Rachel, a young girl with multiple disabilities, who is inspired by the dancing in her church's worship services. June, a young woman with Down syndrome, carried the cross in her Episcopal church. An adult with the label of mental retardation enjoys watching baptisms in his church. Little Jenny's church has come together to raise money to help pay for her care. The author looks at how the presence of people with disabilities in churches challenges the church to adopt a more welcoming attitude towards people with disabilities–which he calls their "rightful place."

TITLE: God plays the piano, too: Spiritual lives of disabled children

AUTHOR: Webb-Mitchell, B.

PUBLICATION INFORMATION: 1993

Crossroad Publishing Company
370 Lexington Ave.
New York, NY 10017
1-800-395-0690

COST: $21.95

This collection of stories tells the spiritual lives and awareness of youths with developmental disabilities such as mental retardation, autism, and behavioral disorders. For example, young Joshua, who has autism, uses his piano playing as an expression of his faith. This book is unique in that it seeks to present first-person narratives of people with disabilities rather than presenting what non-disabled people think people with disabilities are thinking with regards to their faith. Included also are the thoughts of people with disabilities living in the L'Arche London, England community where Webb-Mitchell, a Presbyterian minister, spent several months carrying out an ethnographic study.

TITLE: Unexpected guests at God's banquet: Welcoming people with disabilities into the church

AUTHOR: Webb-Mitchell, B.

PUBLICATION INFORMATION: 1994

Crossroad Publishers
Publisher Resources, Inc.
1224 Heil Quaker Blvd.
P. O. Box 7017
La Vergne, TN 37086
1-800-937-5557

COST: $17.95

Written by a Presbyterian minister, this book talks about how people with disabilities can be included in congregational life. The book contains eight chapters which look at topics including a theological reflection of the place and the presence of people with disabilities in faith communities, Christian religious education, and inclusive congregational life.

TITLE: Attitudes towards disabilities found in the Talmud

AUTHOR: Wertlieb, E. C.

PUBLICATION INFORMATION: 1988

Journal of Psychology and Judaism, 12(4), 192-213

This article details and analyzes Talmudic accounts of disability. It is a thorough and comprehensive source which can serve as an excellent reference, especially for those in observant communities who wish to integrate this material into modern Jewish law and practice. Wertlieb guides the reader through concepts and terms that may not translate into current definitions of disability and situates them within specific religious, political, and historical contexts.

TITLE: Judaism as a support system for Orthodox Jewish parents of mentally retarded children

AUTHOR: Woolfson, R. C.

PUBLICATION INFORMATION: 1985

Journal of Jewish Communal Services, 61(3), 257-260

Many parents of people with mental disabilities feel isolated from their religious community, and feel burdened with responsibility, guilt, doubt, and shame. This article reframes the situation in a positive way for the religious Jewish families. Woolfson reframes many of the challenges that these families face to positive Jewish principles: self-acceptance, crisis as challenge, loving kindness (*chesed*), respect (toward all people), education (for all), participation in ritual practice, self-help skills, and prayer. In this sense, a family that felt marginalized could actually be understood positively.

Resources on L'Arche

L'Arche is an international federation of intentional faith communities where people with and without disabilities live together in life-sharing situations. Founded in 1964. in France by Jean Vanier. today over 104 L'Arche communities are found in 25 countries around the world. Also connected with L'Arche are *Faith and Light* communities which bring together people with disabilities. their families. and their friends for times of sharing. prayer. and celebration. L'Arche communities were the first intentional life-sharing communities to outwardly welcome people with disabilities. In this sense. the numerous writings on L'Arche which focus more so on life in a faith community. personal spirituality. and inclusion of people with disabilities in the Church can be insightful for those working toward inclusion. However. it is also important to point out that life-sharing situations within intentional faith communities are a unique and specific way in which some people can choose to enact their faith lives and are by no means 'the' only way in which people with disabilities should be allowed to enact their faith. Below are annotations of writings on L'Arche that relate specifically to the roles and places of people with disabilities in the church. inclusiveness in the church. and the support of people with disabilities in their own spirituality. A catalogue of a full list of resources on L'Arche can be ordered through Daybreak Publications at:

Daybreak Publications
11339 Yonge Street
Richmond Hill. ON L4S 1L1
CANADA
1-800-853-1412

More information on L'Arche can be found at the following Internet web site:

http://www.larchecanada.org

The following three books are from a new L'Arche Collection published by Novalis. This collection is designed to help readers integrate the spirituality of L'Arche into their everyday lives and to acquaint the whole church with the experience of L'Arche communities.

TITLE: An ark for the poor: The story of L'Arche

AUTHOR: Vanier, J.

PUBLICATION INFORMATION: 1995

Novalis
49 Front Street, East, 2nd Floor
Toronto, ON M5E 1B3
CANADA
(416) 363-3303

In *An ark for the poor*, Jean Vanier documents the history of L'Arche. Starting with the founding of L'Arche in 1964 by Vanier and two men from a local institution, Vanier traces the history of L'Arche, in five-year periods, as it grew from a single family home into what is now an international federation of over 100 communities. Specifically, he looks at: the founding, the expansion, growth of family, growth in maturity, structuring L'Arche, and questions today facing L'Arche and faith communities that support people with disabilities in their spirituality. Also included, in Appendices, are the Charter of L'Arche as written and adopted by the General Assembly of the L'Arche Federation in May of 1993 and a list of L'Arche communities around the world.

TITLE: The heart of L'Arche: A spirituality for every day

AUTHOR: Vanier, J.

PUBLICATION INFORMATION: 1995

Novalis
49 Front Street, East, 2nd Floor
Toronto, ON M5E 1B3
CANADA
(416) 363-3303

In this second book of the Novalis series on L'Arche, Vanier describes in detail, for those familiar and unfamiliar with L'Arche, the spiritual philosophy behind L'Arche. Included are discussions on the mystery of faith in the start of L'Arche over 30 years ago; what is meant when L'Arche refers to itself as being centered on a spirituality of the poor; the spirituality of, and life in, an intentional faith community of people with and without disabilities: trust, insecurity, and openness in community life; and the spiritual relationship of L'Arche to the church and the community at-large.

TITLE: Body broken, body blessed: Reflections from life in community

AUTHOR: Mosteller, S.

PUBLICATION INFORMATION: 1996

Novalis
49 Front Street, East, 2nd Floor
Toronto, ON M5E 1B3
CANADA
(416) 363-3303

In *Body broken, body blessed*, Mosteller, who is pastor at the L'Arche Daybreak community in Ontario, Canada, speaks candidly about 'real' life in a faith community. She does this by talking about her 24 years of living at Daybreak, the joys and the sorrows she has experienced there over the years. Mosteller takes a somewhat unique approach in writing her story by relating it to the life experiences of the people with disabilities with whom she lives, thus, telling both her and their stories. She talks about L'Arche as a place: that is home, of safety, of individuality, where history is enjoyed, where fears can be confronted and beauty discovered, to hold loneliness, to surrender control, and to die.

Newsletters

TITLE: The Common Thread

AUTHOR: Community and Relationship Building Project

PUBLICATION INFORMATION:

c/o UCP
4638 Centre Ave.
Pittsburgh, PA 15213

Although this newsletter does not center specifically on the inclusion of people with disabilities in faith communities, it does often includes articles related to this area and community inclusion in general. For example, recent issues have included articles on hearing Jean Vanier founder of L'Arche speak, Bill Gaventa's Rosh Hashanah story, and the gift of a stranger. Especially nice are the quotations included, such as this one from J. R. R. Tolkien: "All that is gold does not glitter, not all those who wander are lost."

TITLE: Council for Jews with Special Needs, Inc. Newsletter

AUTHOR: Council for Jews with Special Needs, Inc.

PUBLICATION INFORMATION:

Council for Jews with Special Needs, Inc.
32 West Coolidge, Suite 102
Phoenix, AZ 85013
602-277-4243
TDD 602-277-4243

This newsletter is published three times a year and places an emphasis on working as a community to ensure that all Jews have the opportunity to fully participate in the richness of Jewish religious, cultural and social life.

TITLE: Disability Solutions – Volume 1, #4

AUTHOR: Enoch-Gelbard Foundation

PUBLICATION INFORMATION:

Disability Solutions
9220 S. W. Barbur Blvd. #119-179
Portland, OR 97219-5428
(503) 244-7662
email: dsolns@teleport.com
http://www.teleport.com/~dsolns

Disability Solutions is published 6 times a year, is free-of-charge, and is a resource for families and others interested in people with Down syndrome and related disabilities. This particular issue focuses on the inclusion of people with disabilities in faith communities. Issues written about include: the church coach, religious inclusion, embracing kids with disabilities in Sunday school programs, including people with disabilities in Jewish life cycle events, and a resource list. The entire issue is available to people with web access as an Acrobat reader file (you can download this reader program for free at http://www.adobe.com/acrobat/readstep.html).

TITLE: NCPD National Update

AUTHOR: National Catholic Office for Persons with Disabilities

PUBLICATION INFORMATION:

NCPD
P.O. BOX 29113
Washington, D. C. 20017-0113
(202) 529-2933 (Voice/TDD)

A free quarterly publication, also available in Braille, large print, and on cassette, the NCPD National Update examines current issues of spirituality, advocacy, and education (religious and school) facing faith communities and people with disabilities in the work to include people with disabilities in these communities. For example, the 1997 summer issue looked at the recent Supreme Court decision on physician-assisted suicide and the vigil held prior to the Supreme Court decision with the disability rights group Not Dead Yet. Other issues typically included in NCPD include: understanding and influencing the perceptions of people with disabilities, inclusive ministry design, advocacy in parishes, education and employment, and other issues of social justice.

TITLE: NAPMR Quarterly Journal and Newsletter

AUTHOR: NAPMR

PUBLICATION INFORMATION:

NAPMR – National Apostolate with People with Mental Retardation
4516 30th Street, NW
Washington, DC 20008
1-800-736-1280

Since 1968, the National Apostolate with People with Mental Retardation has produced a quarterly journal and a newsletter six times a year. Regular issues discussed are: inclusive religious education for adults and children, advocacy–including self advocacy, program development – housing options, conferences, spiritual formation, and family.

TITLE: That all may worship: Newsletter of the New Jersey Coalition for Inclusive Ministries

AUTHOR: New Jersey Coalition for Inclusive Ministries

PUBLICATION INFORMATION: Quarterly

New Jersey Coalition for Inclusive Ministries
The University Affiliated Program of New Jersey
UMDNJ-Robert Wood Johnson Medical School
45 Knightsbridge Rd., P. O. Box 6810
Piscataway, NJ 08855-6810
(732) 235-4408

A new interdenominational newsletter produced quarterly by the New Jersey Coalition for Inclusive Ministries, this newsletter looks at various topics regarding the inclusion of people with disabilities in faith communities. Recent topics have included: how Jewish group homes can be sensitive to the needs of their practicing residents, how congregations can reach out to people living in group homes to include them in their faith communities of choice, and how to remodel faith communities to make them more accessible to people with disabilities. The first issue includes the results of a survey on accessibility and inclusivity from 410 congregations in NJ. Lists of new resources–paper and Internet–are always included as is a list of upcoming events and news from different congregations.

Mission & Pastoral Statements

TITLE: Charter of the Communities of L'Arche

AUTHOR: General Assembly of the Federation of L'Arche

PUBLICATION INFORMATION: 1993

The Hearth
523 West 8th Street
Erie, PA 16502
(814) 452-2065

The Charter of L'Arche outlines the underlying principles and aims of L'Arche communities, the key aim of which is to "create communities which welcome people with a mental handicap," and the key principle that whatever our gifts and limitations, "people are all bound together in a common humanity." Also included are statements on the L'Arche communities themselves–communities called to: lives of faith; a covenant of unity; growth in love, self-giving, and wholeness; and integration into the community at-large–both religious and secular. Finally, the concern of L'Arche with social justice for and work against rejection of people with disabilities is expressed.

TITLE: Pastoral Statement of U.S. Catholic Bishops on People with Disabilities

AUTHOR: National Catholic Office for Persons with Disabilities (NCPD)

PUBLICATION INFORMATION: 1978, Reprinted with updated language, 1989

NCPD
P. O. BOX 29113
Washington, DC 20017-0113
(202) 529-2933 (Voice/TDD)

This position statement was written at the 1978 United States Catholic Conference and had its language updated in 1989. Taking a very clear stand that people with disabilities must be ensured a secure, welcoming, and full participatory place within the church, this NCPD position statement points out ways in which people with disabilities may be included at the parish, diocesan, and national level of the Catholic church. Specific issues discussed are acceptance, advocacy, dignity, education, faith, family, lay readership, legislation, prejudice, and accommodations (such as sign language interpretation and transportation). These issues are discussed within an underlying philosophy of, "it is not enough merely to affirm the rights of people with disabilities. We must actively work to make them real in the fabric of modern society."

TITLE: NCPD Mission Statement

AUTHOR: National Catholic Office for Persons with Disabilities

PUBLICATION INFORMATION: 1995

NCPD
P. O. BOX 29113
Washington, DC 20017-0113
(202) 529-2933 (Voice/TDD)

Approved by the NCPD Board of Directors in the Spring of 1995, this is the mission statement of the NCPD. The overriding mission of the NCPD is to realize "the unique gifts individuals with disabilities have to offer the Church (and) the need for their integration into the Christian community and their fuller participation in its life." The NCPD aims to accomplish its mission through cooperation with other Catholic ministries for persons with disabilities (such as, the NAPMR), assisting diocesan officers and directors in ministering to people with disabilities, acting as a resource, and so on.

TITLE: NCCC policy statement on disabilities, the body of Christ, and the wholeness of society

AUTHOR: NCC Committee on Disabilities

PUBLICATION INFORMATION: 1995

NCCC Human Rights: The Fulfillment of Life in the Social Order
NCC Committee on Disabilities
c/o Ministries in Christian Education
National Council of Churches of Christ
475 Riverside Drive, Room 848
New York, NY 10115

This position statement on roles of people with disabilities in the Church was adopted by the General Board of the NCC Committee on Disabilities on November 17th, 1995. Based on the biblical reference 1 Corinthians 12:14, "Indeed, the body does not consist of one member but of many," this policy statement rests on four theological principles: (1) all people are created in the image of God, (2) all people are called by God, (3) all people have special gifts, and (4) all people are invited to participate in God's ministry. Implications to these theological principles are also looked at.

TITLE: The care and education of Jewish retarded children

AUTHOR: Schneerson. M. M.

PUBLICATION INFORMATION: 1979

Rabbi Menachem M. Schneerson
Lubavitch
770 Eastern Parkway
Brooklyn. NY 11213

Rabbi Menachem M. Schneerson. Rebbe of Lubavitch Hassidim Jewish community. in 1979. wrote a three page letter in response to a question by a member of his community who is also a chairman of a regional council for mental retardation. The Rebbe was asked whether a child who is considered to have a developmental disability should be fully immersed into Jewish education and full participation in community and Jewish rituals–would this not be "doubly taxing" given their limitations to succeed in even the basic education.

The Rebbe write in no uncertain terms that each child has potential as well as a right to Jewish education and full participation in community rituals. He said that it provides for either a "conscious or subconscious inner security" and a sense of "belonging and anchorage." It is our obligation to each Jewish child "without exception."

Rebbe Schneerson also spoke in 1978 on the idea that each Jewish child has a right to a Jewish education and that they should be entitled to full acceptance in the community. He said that all children have potential. regardless of labels placed on them by professional or developmental expectation. He said that although we have to be realistic. we can still have high expectations: realistic and ambitious.

Organizations

Aurora Ministries Bible Alliance
P.O. Box 621
Bradenton, FL 34206
(914) 748-3031

Aurora Ministries provides free copies of the Bible—Old and New testaments—on audio cassettes, to organizations who support persons with visual impairments or other disabilities. To order a copy write to the above address or call the above telephone number.

Council of Jews with Special Needs, Inc.
Becca Hornstein, Exec. Director
32 West Coolidge Suite 102
Phoenix, AZ 85013
(602) 277-4243

The Council for Jews with Special Needs is a non-profit human resource agency, composed of concerned individuals working together to ensure that all Jews have the opportunity to fully participate in the richness of Jewish religious, cultural and social life. The Council serves individuals with special needs who are physically, mentally or emotionally handicapped or learning disabled and their families. The Council's efforts shall include both integrated and specialized programming, family support groups, information and referral, community education and effective networking with other Jewish agencies to achieve full accessibility for Jews with disabilities. There is a charge of $36.00 to be placed on their mailing list.

Health and Welfare Ministries – DISC
United Methodist Church
Room 330, 475 Riverside Dr.
New York, NY 10115
1-800-UMC-GBGM
TDD: 212-870-3709
http://gbgm-umc.org/DISC/

DISC is one of the ministries under the umbrella of the United Methodist Church's Health and Welfare Ministries that address the critical health needs of children, youth, older adults, people with disabilities, and racial/ethnic communities. It also has a computerized AIDS Ministries and Disability Concerns electronic bulletin board services and two noteworthy

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resource lists are: "Access and Inclusion: An Interfaith Resource List," and "Annotated Bibliography on Developmental Disabilities and the Church" (the later at: http://gbgm-umc.org/DISC/ddbib.html).

Institute for Pastoral Initiatives
University of Dayton
Dayton, OH 45469-0317
(937) 229-4325
TDD: (513) 229-4356
http://www.udayton.edu/~ud-mwpd

Formerly the Center for Ministry with People with Disabilities, and now under the umbrella of the Institute for Pastoral Initiatives, this group's mission is to facilitate the acceptance of people with disabilities into church communities at the local, state, and national level. They also work to assist the University of Dayton to prepare its students to be "morally aware and committed" in relation to people with disabilities. Available by calling and asking are an excellent list of videos on faith inclusion for people with disabilities, a list entitled, "More than 50 Ways to Make your Parish Accessible With Little or No Cost Involved," a check list to monitor accessibility of your worship building, and discussion starters for making your place of worship more inclusive.

L'Arche and Faith & Light Communities

for L'Arche:
The Hearth
523 West 8th Street
Erie, Pennsylvania 16502
(814) 452-2065

for Faith and Light:
305 Michigan Ave.
Detroit, MI 48226
(313) 237-4664

L'Arche was founded in 1964 in France by Jean Vanier and Father Thomas Phillipe, when Vanier welcomed Raphäel Simi and Phillipe Seux, two men with developmental disabilities, to come and live with him in a life sharing situation based on the Beatitudes of the Bible. With time L'Arche grew into what is now an international federation of intentional faith communities. More recently Faith and Light communities were formed for those not wishing to live in a life sharing situation, but who wished for places of worship to welcome where people with disabilities of all ages and their families and friends would be welcomed. Faith and Light communities generally meet once a month to share a meal and prayer time. Although L'Arche was founded in the Roman Catholic tradition, today other communities have developed in various cultural and religious traditions including Orthodox Christian, Roman Catholic, Episcopalian, United Church, Jewish, and Hindu, while remaining united in a common vision and spirit of welcoming, sharing, and simplicity. A video on Faith and Light can be ordered from the Institute for Pastoral Initiatives.

Mental Retardation Sabbath/Sunday Project
The Arc – National Headquarters
500 E. Border Street, Suite 300
P. O. Box 1047
Arlington, TX 76004
(817) 261-6003
http://TheArc.org/welcome.html

The Mental Retardation Sabbath/Sunday Project has been an annual project of The Arc since 1979 to help "acquaint the general public with the needs of people with mental retardation and their families living in the community." This is done by having congregations focus some part of their Sabbath/Sunday religious service on ministry to people with disabilities and their families, to name two examples, by inviting a person with a disability or a family member to give a sermon and encouraging people to come forth as support people for those who need support during services.

National Apostolate with People with Mental Retardation
4516 30th Street, NW
Washington, DC 20008
1-800-736-1280

First established in 1968, NAPMR is now a national organization under the Catholic church with people with disabilities. It publishes a quarterly journal and a newsletter six times a year. Based on a philosophy of inclusion for all, NAPMR works to ensure that people with disabilities become equal partners in the Christian community and to educate religious leaders to fully appreciate the contribution that can be made to the Church by people with disabilities. It offers various membership levels, which are open to people of all denominations. Also available for free is a booklet they put out entitled, *Welcome to God's Word*, a guide for parents of children newly diagnosed with developmental disabilities.

National Catholic Office for Persons with Disabilities (NCPD)
P.O. Box 29113
Washington, DC 20017-0113
(202) 529-2933 (Voice/TDD)

Starting as a ministry in 1978 to coincide with the release of the *Pastoral Statement of US Catholic Bishops on People with Disabilities*, the NCPD reaches out to support parishes and families with a member with a disability in the inclusion of people with disabilities in the Catholic church. NCPD has a mission statement and a quarterly newsletter entitled *NCPD National Update* (both cited in this package), responds to inquiries for information on inclusion, participates in national disability activism, and overall works for the inclusion of people with disabilities.

National Christian Resource Center (NCRC)
Bethseda Lutheran Homes and Services, Inc.
700 Hoffmann Dr.
Watertown, WI 53094
(800) 383-8743

This center provides free materials and information on residential services, advocacy, respite care, and religious programming through its computerized database. It also provides videos on religious education for people with disabilities and publishes a quarterly newsletter called *Breakthrough*, on these same issues.

National Jewish Council for the Disabled/Yachad
333 7th Ave
New York, NY 10001
(212) 613-8229
yachad@ou.org

Sponsored by the Orthodox Union, this national council provides social, educational, and recreational programs for Jewish youths and young adults with disabilities within mainstream programs through friendship, "yachad." They also sponsor tours, open to people with and without disabilities, to Florida and to Israel. Tours to Israel include visiting a Kibbitz, Jerusalem, the Western Wall, and other noted Jewish sites of interest.

National Organization on Disabilities
910 Sixteenth Street, N.W., Suite 600
Washington, DC 20006
1-800-248-2253
TDD: (202) 293-5968
http://www.nod.org

This National Organization on Disability (NOD) promotes the full and equal participation of men, women, and children with disabilities in all aspects of life, including religious life. Founded in 1982 at the conclusion of the United Nations International Year of Disabled Persons, NOD is a key national disability network of organizations concerned with all disabilities, all age groups, and all disability issues. Through the support of the Scaife Family Foundation, the NOD Religion and Disability Program urges local congregations, national denominational groups and seminaries to remove architectural, communicational, and attitudinal barriers. The Religion and Disability Program can be reached at the above address or by email at religion@nod.org

National Task Force on Developmental Disabilities
United Methodist Church
503 Vine
Leavenworth, KS 66048
(913) 682-8517

This Task Force was started in 1992 to provide leadership and resources for lay persons and clergy in ministry with people with developmental disabilities. Areas of focus include models of ministry, self advocacy, educating congregations, local church inclusion, and theology of inclusion.

New Jersey Coalition for Inclusive Ministries
The University Affiliated Program of New Jersey
UMDNJ-Robert Wood Johnson Medical School
45 Knightsbridge Rd., P.O. Box 6810
Piscataway, NJ 08855-6810
(732) 235-4408

The New Jersey Coalition for Inclusive Ministries is an interfaith network, including Christian, Islamic, and Jewish religious groups, service and advocacy organizations, congregations, individuals, lay people, clergy, families, and people with and without disabilities who are all committed to: *supporting faith communities in working to fully include all people with disabilities or special needs as valuable members.* Some of the ways in which this goal is accomplished by the Coalition is by fostering dialogues, meeting for information exchange, offering workshops and conferences, celebrating people with disabilities who are already active in faith communities, and referring clergy and lay persons to appropriate resources. Membership fees per year–which provide various benefits including newsletters subscription–are $100 for organizations, $25 for congregations and $10 for individuals.

Pathways Awareness Foundation
123 N. Wacker Drive
Chicago, IL 60606-1700
1-800-955-2445
TDD: (312) 236-7411
http://www.archdiocese-chgo.org

Established in 1988, as a not-for-profit organization, the Pathways Awareness Foundation is dedicated to education for and about children with disabilities. Although the Foundation's mission is to raise public and professional awareness about early detection and early intervention, they also now focus on inclusion of children and youth with disabilities in houses of worship. At present, Pathways is working in partnership with the Chicago Roman Catholic Archdiocese to help promote the inclusion of people with disabilities in mainstream worship.

Religion Division
American Association on Mental Retardation (AAMR)
c/o the Rev. William Gaventa
31 Alexander St.
Princeton, NJ 08540
(908) 235-4078

The Religion Division of the AAMR is an interfaith, interdisciplinary association of professionals and ordained and lay people who are concerned with people with developmental disabilities and their families. The mission of the division is to share resources which provide for opportunities for spiritual growth for people with disabilities, while respecting their religious identity. The division has a newsletter available for clergy, congregations, and others who are interested in keeping up-to-date with resources and ideas for ministry and supports for people with disabilities.

Yad B'Yad Jewish Community Inclusion Project of Greater Buffalo
2640 North Forest Rd.
Getzville, NY 14064
(716) 688-4033 x343

Yad B'Yah, the Hebrew expression for "hand-in-hand," is a non-profit outreach and advocacy project that assists Jewish agencies and synagogues in helping Jewish people with physical, mental, or emotional disabilities achieve full participation, membership, and inclusion in Jewish activities and organizations. The purpose of these efforts is to enrich the spiritual and communal lives of Jewish people with and without disabilities by expanding friendships, sharing mutual talents and gifts, and fostering an appreciation of individual differences. The ultimate aim is to further K'lal Yisrael, which promotes a sense of belonging and community for all Jewish people.

Reprints

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A Rosh Hashanah Birthday

—William C. Gaventa, Jr.

It wasn't such an unusual scene, I thought, for a temple. A little boy, a middle-aged woman, an old man...all gathered around the rabbi after the Rosh Hashanah service to examine the Torah. They touched, felt, looked, and wondered. The rabbi had spoken that evening of each of us recovering childlike wonder...wonder at creation...wonder at God...wonder at the gift of belonging to his people. As the rabbi pointed out the parts of the scrolls and its coverings, *wonder* was the only word for the expression in the boy's eyes as he gazed at the strange writing and at the two companions he suddenly found with him.

And I wondered, will he ever know? Would he, or anyone, know of the vast differences between them that simply melted away in the moments of that age-old experience? At that moment they were tied together by a common tradition. Their journeys, which had been so different, were now one.

For the Torah has been brought at the request of Harry. Harry was the oldest of three, going on 75. Three score and ten plus some, and still going strong. He had gone up to the rabbi after the service and said what he had whispered to me near the end of the service,

Can I kiss the Torah?

As if the rabbi didn't have anything else to do, I thought, for there were hundreds of people there. I thought to myself: *Kiss the Torah? Harry, let's wait till another time. Wait till we come back. It has gone well tonight. Don't cause a scene now.*

But the rabbi, with patience, had simply said,

Let's wait a bit, Harry, till people clear out.

And we did.

While we waited, Harry introduced himself to the other rabbi.

> *Rabbi, my name is Harry. I'm from New York City. My brother, he sent me to Craig Colony, and now I'm here.*

I thought to myself, here we go again.

Harry does have a story to tell, and it goes out to every one he meets, especially if they are Jewish. Every rabbi who came to the center where he lives heard the story at the biweekly Oneg Shabbat services. And his story, according to Harry, is something like this:

> *I'm from New York City. My grandfather, he sent me to Hebrew school. I was born in England. We moved to Argentina and then to New York. My brother, he sent me to Craig Colony. I didn't have no seizures. I'm 75 years old. My mother, my father—all died. I don't have no sister anymore. My brother, he's in the Jewish home, but I don't know where. The letters the social worker sent all came back. But do you want to hear this....*

Harry will then launch into one of the Yiddish songs he knows by heart, or recite the blessing for the Sabbath. And he'll tell you his grandfather taught him that.

If you stop to hear what he is saying, you realize that for Harry the only real tie he has to his family is that he is Jewish. His only sense of belonging is that he is Jewish. He is angry sometimes, but most of the time he simply wants to tell you his story. He wants to see if you know anything about his people...if you can help get the connections reestablished...to see if your story or your journey crosses his. *I don't belong here*, he seems to say. *I belong with my people. But I don't have any people.* From England to Argentina to New York to Craig Colony to Rochester...*A Wandering Aramaean was my father.*

Harry's story, on this eve of Rosh Hashanah, was stopped only by an overprotective chaplain, who cut in to tell the rabbi something of the significance of the night for the second member of the trio whose members stood looking at each other over the Torah. While Harry had perhaps often been to Temple as a child, from what Sally told us, this was the first time she had ever been. And Sally is 51.

Sally. Talk about endurance, about struggle, about patience, and you simply have to meet Sally. She's not a person many people find it easy to meet. The barriers she faces are too often barriers that other people look at--and then run away from.

One barrier is that she is in a wheelchair. Many never see the person after the wheels.

The second is the reason she is there...cerebral palsy...with severe spasticity. It is a big nasty word which simply means she can't control her arms, legs, and head like others can.

The third barrier is the hardest of all for us who rely on words. She cannot talk. She can mumble, she can murmur, she can sing, she can pray, but the words are not our words. The ability to enunciate as others do is not there. But does she ever understand!

Sally understands. She knows what you are saying. She knows what you mean. She understands people, for she observes, watches, and listens. She knows that life can be pure hell. She knows the world is not fair. She knows that she has had to suffer, in almost geometric progression, because of her handicap. I'll never forget having to help her control her arms and head as some struggling doctors at a local hospital tried to get a tube down her nose to get a specimen to test the degree of her pneumonia. In a world that too often defines dignity in terms of the degree of self-control, Sally didn't stand a chance.

But dignity is what she has: the dignity of a soul that has overcome despair, and overcomes it daily; the dignity of a spirit that never dies; the dignity of a smile and sense of humor that are humbling; the dignity of a curiosity that is forever on the prowl; and the dignity of a faith that literally holds her together.

Every single time in a year and one-half that we had arranged something for Jewish clients, Sally was the first one there. *My soul thirsts for God.*

Every new event...an Oneg Shabbat service, a Hanukkah party, a Passover Seder, a folk dance at the Jewish Community Center, she reveled in them. *Yea my heart is glad in him.* When she sings, as when she prays, the physical effort is twice ours, the words unintelligible, but the beauty is there. *He put a song of praise in my mouth, a song of praise to our God.*

And this evening, finally, was the first time she had ever been in a temple. Why not before? Who knows? Unable? Unwillingness? Unconcerned? Unsure? On whose part?

Certainly not Sally's. I had found myself unsure in the year as we moved toward the possibility for her. I knew she would love it, but would she be welcome? Would people see Sally inside, not outside? Would people stare at her, or at me? Who was I protecting?

Wait for the Lord, be strong, and let your heart take courage. When I finally got my courage together, and the gates of the temple seemed open, thanks to a caring rabbi, I finally told Sally we might be able to go to the Rosh Hashanah service.

Her response made every possible and foreseeable indignity on my part seem so small. She jumped at my words with heart, soul, mind, and body. *I waited patiently for the Lord, he inclined to me, and heard my cry.* People often say that people like Sally will receive the rewards for their suffering in heaven. But for Sally, life is now. Believing is now. Belonging is now. The rabbi spoke that evening of being Jewish, meaning being more than what one believes. It is also the feeling and reality of belonging. She also spoke of being Jewish, meaning being a *choosing* as well as a *chosen* people. Sally chose. Sally knew. Sally waited. And Sally triumphed. The rabbi at the pulpit and the Rosh Hashanah card in everyone's pew both said that Rosh Hashanah was an evening commemorating the birthday of the world. It was for Sally's world. *I believe that I shall see the goodness of the Lord in the land of the living,* says the psalmist. If it happened once, it can happen again.

So there we were. Harry. Sally. Naomi, beaming with pride because of her mother in the choir. Mark, saying all the words at the end of the sentences of the prayers, three seconds behind us, but saying them. Two Hillel students had also come with us, one of them away from home at Rosh Hashanah for the first time. An Old Testament professor, husband of Sally's recreation therapist, read the Hebrew to her during the service. And me. What a motley band.

And there was the little boy. Now, at the end of the service, as the rabbi brought the Torah out, she helped Sally to touch and to feel, and let Harry hold. Some other adults saw the scene, and brought over the child--round face, wide eyes, blonde hair. They said he was from Russia, and that this was the first time in his life of eight years he had even been able to be at a service in a temple. He and his family had been forced into exile from their home in order to be free to be who they are. Harry...coming out of decades of exile--finding a bit of who he was. And Sally, in bondage, but yet free...celebrating who she was, has been, and, hopefully, will be. Differences in ages, nationalities, and abilities melted away in a moment when their journeys were truly one, bound together, as they always have been, by a single story: *I am the Lord your God, who brought you out of the land of Egypt,* by an ancient scroll: *My delight is in the law of the Lord,* and by a common song: *Let the people praise Thee. Let all the people praise Thee. Amen!*

How the Religious Community Can Support the Transition to Adulthood: A Parent's Perspective

Becca Hornstein

Transitions are a universal experience for all of us, are times of elation and depression, adventure and trepidation. We linger, not quite certain about letting go of what we know before we rush headlong to embrace the unknown. You have experienced this yourself, perhaps when you awaited the arrival of your first child.

I still remember my dreams about my baby's future. They extended just beyond the horizon formed by my burgeoning belly. My husband and I talked constantly about the baby-to-come. Barry wanted a basketball team; he even joked about naming our first born "Meadowlark"! I dreamed about practical things, like, would the baby look like his daddy or his mommy? In fact, one night I had a remarkably clear vision of the baby I was carrying. Being more than a little superstitious, I believed this was a divine message. I awoke and immediately drew a picture of the child nestled in my body. I sketched a drawing of a delicate, blonde-haired, blue-eyed baby girl. About a month later, I gave birth to a husky, black-haired, brown-eyed little boy! So much for the reliability of dreams.

Yes, so much for the reliability of dreams. I learned that lesson quickly as Joel's disability, autism, surfaced at age 21 months. We went from doctor to doctor, therapist to therapist, city to city looking for answers about Joel's condition. It took 2 years to get a diagnosis . . . and it was quickly followed by a devastating prognosis: This child will never be anything but profoundly mentally retarded, will never speak, will never acknowledge your existence, will never be toilet trained or feed or dress himself . . . this child will never be capable of giving or receiving love. If I had any dreams left before that prognosis, they were destroyed at that moment.

But it is not fair to take away parents' dreams! Dreams are what give us the motivation to make it through those scary, difficult transitions. At first, Barry's and my dreams were born of desperation: Oh Lord, will this child *ever* be toilet trained?? Will he ever sleep for more than 2 hours a night?? Some were practical: Please talk to us, Joel. Please look me directly in the eye and acknowledge that I exist in your world! And some were silly: Oh, Joel, whatever will you do when you grow up??? You have phenomenal math skills, Joel; have you considered going into the stock market? You learned to play the piano in just 2 hours; maybe we can find an autistic piano bar to hire you!

But when silliness subsides, we had to seriously consider how to prepare Joel for his transition into the adult world, and we could not wait to begin that process until our son was 18. The first step toward planning the future for a child who has a disability should start very early. It necessitates taking a realistic look at that child: his or her strengths and weaknesses, skills, and behavior. We needed to honestly assess Joel and his finger-flipping, echolalia-spouting, and extreme vulnerability. From that appraisal, we started to set goals for the future.

Because children with developmental disabilities need extra time to learn things and because behaviors that become implanted are hard to extinguish and redirect, it is important to lay the foundation early for good adult living skills. For example, we gave Joel household chores to teach him to respond to directions and to learn about "cause and effect": Empty the trash, set and clear the table, make your bed . . . and you receive a reward! To make that reward meaningful, it either had to be something Joel wanted or, later when Joel understood delayed gratification, a token that he understood would translate into something he wanted.

It took a long, long time to teach Joel the concept of money. For children who have cognitive impairments, the concept of currency and wages is too abstract. After all, it appeared to be just a bunch of wrinkled green paper and shiny circles. Ah, but we *knew* the day Joel finally comprehended marketplace economy. He had been out spending his allowance with a friend, ran out of money, and came bounding into the house. He rushed up to me, waved his empty wallet in my face and said, "Dollars are all gone—fill 'er up, Mommy!" Children's chores are the earliest forms of vocational training, and allowance is the introduction to a paycheck.

Joel loves a schedule, and we used one at home and school. Because Joel was fixated on numbers and letters, he learned the concept of time at a very early age. His teachers and I discovered that we could alleviate his anxiety about the uncertainty of his life by giving him a daily, written schedule. It reassured him that there was a pattern to his daily routine, and children with autism are comforted by repetition in their lives. Joel was more flexible than some, and we could alter his schedule, as long as we did it in front of him, crossing out what was deleted, and writing in what was added. Remember the scene in *Rainman* where Dustin Hoffman's character reminds everyone that "It's 5 minutes to Wapner!"? Learning to follow a schedule from an early age established a pattern that Joel continues to use in his job today. His work assignments are in half-hour blocks and are posted on a daily worksheet for him to read. Of course, he also reads and monitors every *other* person's schedule and has been known to loudly announce anyone's deviation from that schedule! Using a schedule, though it may seem rigid and stultifying for some, provides the structure for adult responsibilities in the work place as does developing a social calendar for some people who have cognitive impairments.

Another essential early lesson was teaching Joel how and when to seek help. Many parents focus so completely on teaching their child with a disability to be fully independent that they sometimes miss an important point. Those children may feel it is announcing failure or defeat to seek assistance, when it is actually quite appropriate sometimes. There are also times in the adult world when insisting "I can do it myself!" is counterproductive. Employers need to see in potential employees the ability to work as part of a team. As adults, in jobs or out in the community, individuals with disabilities will need to learn how to evaluate situations and determine when asking for help is the best solution. Joel has profound communication difficulties, and this has created the need for the staff members in the library where he works to accommodate his needs sometimes. For example, when he needs help in sorting a particular book, Joel tends to take the library book in question and just aim it in the direction of a librarian. Everyone is working hard on teaching him to verbalize his request for help. Recently, while Joel was shelving books in the public area, he was muttering to himself, in true autistic fashion. A library patron told Joel to "shut up"! but Joel did not realize the man was addressing him. The man got angry and screamed at Joel in more vulgar terms to "Shut up"! By the time this man was hovering over Joel and shouting at him, a staff member intervened. When the patron was informed that Joel was an employee who had a disability and did not understand what the man was saying to him, the man said, "They shouldn't let *those people* out of their institutions. They should keep 'em locked up . . . they're disgusting!" The good news is, Joel didn't understand that either. From this experience, we realized Joel still needs to learn how to recognize potentially dangerous situations and to seek help.

Although there are many more ways to prepare children for the adult world of work and play, the most important lesson may be learning how to interact with those around you. More jobs are lost by people who have disabilities because they act inappropriately in the lunch room than for any other reason. Joel does not chat with his co-workers in the employee lounge, but neither does he manifest the rocking, chattering, self-stimulation behaviors that might stigmatize him as different, disabled. During these times of relaxation, undistracted by their library tasks, Joel's co-workers might find his "differences" more alarming and unsettling.

Opportunities to Support Transitions in the Religious Community

How can the Jewish community provide support and assistance to families of children with disabilities as they move toward transition? In our day and supplemental schools, we can build a warm, accepting place for each and every child. Our schools become microcosms of society, a training ground in which to learn the kinds of skills I have just described. In an academic setting where ethical behavior, "gemilut chasidim" (deeds of loving kindness) and "tikkun olam" (healing the world) are part of the curriculum, teachers can guide all students through lessons covering such topics as when to help someone and when to enable others to help themselves. Challenging social situations can be constructed and appropriate responses modeled for group discussion. Students with mental or physical impairments can learn to advocate for themselves in a safe environment;

their peers provide the best role models as well as influential counselors to impress upon them the importance of issues such as shared responsibility, promptness, attention to detail, setting and reaching goals. Teachers can learn how to include systems of tasks and rewards in a child's curriculum as well as providing opportunities for students with special needs to learn to make choices, all skills that will be used in adult life on a daily basis.

Our Jewish community centers, camps, youth groups, and social clubs provide an additional opportunity to prepare for life among the general population. In all of these settings, the essential ingredient is "reality." Children and teens with disabilities must learn how to manage in the fast-paced world of typical people, a world that will not always slow down to accommodate them. When my agency placed Gary, a boy with Prader-Willi syndrome, in summer camp, we knew his condition included obsessive eating. We used the camp setting to teach Gary, away from home and school, the consequences of grabbing other people's lunches or snacks and how to work on his own behavior in a new, different setting. For Sammy and Dina, both of whom are deaf, our camp counselors were instructed to fade away from being the children's ever-present interpreters as soon as possible. Camp became a training site for them to develop communication skills outside the protected, insular bubble of special schools. For Leah, who has Down syndrome, and Ari, who has been blind since birth, participation in synagogue youth groups meant learning to employ self-advocacy techniques on a frequent basis.

The Jewish social service agencies must offer workshops and supports systems for families and teens-about-to-become-adults long before the safety net of the public school years falls away. Those agencies should offer support groups for individuals who have a disability and for family members; mentoring programs for experienced parents to assist those who are just learning how the system works; social skills training for teens and adults with special needs; and informative workshops on issues that are relevant to those who have a disability. I am amazed at how many parents are uninformed and unprepared to apply for SSI, consider the pros and cons of guardianship, and tackle the Byzantine rules of government programs and entitlements. Every Jewish Family and Children's Service in the country should have at least one social worker on staff who can help a family work their way through these issues.

Finally, our congregations can assist families in the most important way. If children with disabilities become active and frequent participants in Sabbath and holiday services, they will develop a sense of belonging that will carry through for every year of their life. Joel's preparation for his bar mitzvah became a congregational project, and today, 10 years later, the congregants still describe his bar mitzvah as one of Temple Chai's proudest moments. When Joel attends services, he is greeted warmly by a significant portion of those attending. The congregants tell me they feel their brief interaction with Joel brings a special blessing to their Sabbath. When Joel volunteers in the synagogue library or stuffs envelopes for a mailing, he is treated just like every other adult in the group. Joel knows that Temple Chai is a second home, a "safe place" where his participation is valued, and he never questions the appropriateness of his being there. During the period of transition from school to adulthood, when all that is familiar and comforting is taken away from a young adult, being able to return to the security and regimen of weekly prayer and participation in synagogue activities becomes the reassuring anchor during this tumultuous period. Attending services and being greeted by fellow congregants reminds this young adult that he is still respected and valued in his community.

Barry and I have been lucky. Joel made remarkable progress, and we were able to dream again as he made successful transitions from private school to public school, elementary grades to high school, self-contained classes to inclusion. Joel has already made his first transition to the adult world. At age 23, he works full time at the county library, earning a paycheck and paying taxes just like you and me. He has the respect and affection of his co-workers at the library, and he is treated with dignity. Joel has more transitions ahead, when we find a place for him to live outside our home. Having proven wrong those experts who predicted he would never be a capable, responsible person, we continue to dream our dreams and help Joel become the very special young man he is.

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Disability for the

Disability — is it
__ a. a punishment
__ b. a test of faith
__ c. the sins of the fathers visited upon the children
__ d. an act of God
__ e. all of the above
__ f. none of the above

I remember my friend who was valevictorian. His speech is coarse, explosive and lacks several consonants. His muscles and tendons are taut pulling his body into a shape like none other in the universe. To move in space he needs a wheelchair and someone to push it.

He was being featured in the local newspaper — "severely handicapped person who overcame all odds — valevictorian."

He wanted to say, "OK I'm smart, but so are many others. I had friends, family, tape recorders, note takers . . . with help and support individuals with disabilities can do more than you can imagine. Participate. Share. Live fully."

But the reporter ignored his thoughts and asked him about his spiritual depth.

And my friend denied this "spiritual depth" and pleaded for his brothers and sisters with disabilities, for more accommodations, more access.

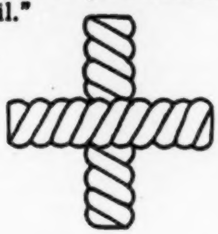
And the reporter ignored his pleas and wrote (only) about his spiritual depth.

And sometimes when I see someone whose body or mind works less efficiently than average, I remember there are people who think "he has great spiritual depth."

Disability — is it
__ a. a punishment
__ b. a test of faith
__ c. the sins of the fathers visited upon the children
__ d. an act of God
__ e. all of the above
__ f. none of the above

Other times I remember a fragile, frightened looking 20-year-old who told me that her grandmother had proclaimed her "possessed by the devil." Took her to an exorcist. Her voice and hands trembled as she went on to say that her seizures had continued. "Then Grandmother said 'take her away — PUT HER AWAY.'"

Sometimes when I hear someone say "seizure disorder" I remember there are people that think "possessed by the devil."



Disability — is it
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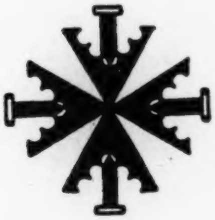
__ e. all of the above
__ f. none of the above

And sometimes I remember being a child, listening to the adults at church talk about injustice.

Whenever people talk about injustice, children with disabilities comes up. When I was around 12, listening to one of these discussions, my mother quoted "the sins of the fathers visited upon the children." I was shocked, then confused.

Some childhood scenes, especially emotionally confusing ones, replay easily in my mind. And sometimes when people talk of injustice and of children born with disabilities, I recall my mother's words and think that there are people who believe "the sins of the fathers visited upon the children."



Religious

by PJ MAGIK

Disability — is it
__ a. a punishment
__ b. a test of faith
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visited upon the children
__ d. an act of God
__ e. all of the above
__ f. none of the above

Sometimes I recall a bright-eyed feisty young woman. She'd been a quad for six years when she told me "God had to slow me down. I was Hell on legs, a defiant druggy. Now my boyfriend calls me his angel — Heaven on wheels."

Sometimes when I see someone using an electric wheelchair I remember her and think "there are people who would say ' act of God.'"

Disability — is it
__ a. a punishment
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visited upon the children
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__ e. all of the above
__ f. none of the above

And sometimes I remember when my former pastor and I were last together, hundreds of miles from home.

He told me news of our church and I smiled clear through myself remembering.

Then he said, "You will heal." And I believed.

Then he said, "You will walk again." And I believed.

Then he commanded, "Take up your bed and walk." I remember struggling hard before I said, "Maybe tomorrow."

It had been a relief to have a visitor that wasn't preoccupied by the traction with its 16 pulleys and 200 pounds of weights, or the 8-inch screws going through the casts on both legs and up through my heel — I thought he saw *me*. But maybe the crushed and shattered and broken and slit-from-the-top-to-bottom bones were me, or part of me.

Then he said, "If you were right with God . . ."

"What? If I were right with God? I am right with God."

But he didn't believe and as he was leaving I heard him proclaim, "You will walk out of here within two weeks."

I was sad that I'd disappointed him by not being his miracle.

He had said two weeks. I had two calls in those two weeks.

Rrrring. "Hello." "Heal thyself." Click, Dial tone.

And I heard my memory echo, "If you were right with God."

Rrrring. "Hello." "Take up your bed and walk." Click. Dial tone.

And I heard my memory echo, "If you were right with God."

I didn't walk out in two weeks,
or in two times two weeks,
or in two times two weeks
times two,
or in two times two weeks
times two, times two.
It was 26 weeks and *then* I
rolled out and about.

Sometimes when I see one of us whose body or mind works less efficiently than average, I remember, there are people who think "not right with God."

Disability — is it
__ a. a punishment
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Frayed at the Edges:
The Intertwined Threads of Life and Disability

by Mary Jane Owen

The intertwining threads of respect for life and the charge to look past obvious impairments to find the unique gifts and potential of those who live with disabilities have been tightly woven into the richly diverse fabric of our Church. Thus, as we prepare to celebrate life, we again recognize that the container of the human soul is wondrously vulnerable to assaults and traumas.

The gift of life comes in fragile earthen vessels. Those who preach death often base their campaigns on society's fears of the handicaps of the young and the infirmities of the old. As we plan our defense of life, we need to utilize the refreshing insights that are unfolding within the community of disability concerns. Positive changes are taking place for all who live with disabilities in our land today.

Voices from the Frayed Edges

A young mother wept bitterly as she shared her story. "Both my husband and I believe in the sanctity of life. And when I learned my baby would be multiple handicapped, I never considered an abortion. We talked to our priest. He said our child would be a gift from God, but sometimes I'm not sure our parish really believes that. Adam is a loving little boy. So why doesn't the parish welcome him? Does our church really consider him a gift? He needs religious training just like any other child. The whole family feels unwelcome when the parish doesn't have room for Adam."

A colleague called with news that medical scientists had discovered a way to eliminate the condition that had caused her hereditary blindness. Her enthusiasm faded as she explored the methods which would "cure" her disability. It seemed the "treatment" would have altered the genes which were destined to create her. The essence of her total being would have been manipulated, and this "cure" would have resulted in a manufactured version of herself. She wasn't sure what other qualities might also have been eliminated. She liked herself enough as God had created her not to take that risk.

Another woman had been abandoned as a baby because the medical professionals judged the quality of her life as merely vegetative. After years in training and rehabilitation, she became a professional counsellor. A television interviewer once asked her what possible joy she had experienced before she was discovered to be bright. Her reply was quick: "I loved the feel of clean crisp sheets against my skin."

A man who grew up to become the director of the rehabilitation system that previously had judged him as too disabled to profit from their services remembers overhearing the diagnosis given his parents: "Your son will never have any quality of life. You should let him go. If he lives, he will undoubtedly merely exist in a vegetative state." And so he as he rolls onto a stage to address an audience, he begins with a humorous greeting, "I come to address you as a carrot, a radish, or a cabbage, whichever you prefer."

An elderly man in a retirement facility run by a church organization could afford and wished to purchase a motorized wheelchair. The administration refused to allow this purchase because, they reasoned, all the other elderly people, seeing such an example in their midst, would no longer be content with sedentary and easily managed activities.

A successful young man with cerebral palsy told a discussion group at his parish, "I'm scared about some of the 'do-good' campaigns. One plans to wipe out all birth-related impairments within this decade. I have nightmares about the final days of their effort. I hear steps on the porch and a knock on the door. 'We're the MOTHERS. You're the very last one!' What plans do you think they have for me?"

Following a stroke, an elderly parishioner required the use of a wheelchair. She worked hard at her therapy, planning to return to her many activities in her parish. However, when she asked about accessibility to the church building, she was told not to worry about such things. "Now that you are 'homebound' we'll bring you the Host." She asked a friend, "Who bound me?" Her decline into depression was rapid. Life just wasn't the same anymore.

Another woman in Michigan told a group in the parish hall, "I was a little frightened to come here. After all, an attorney recently justified the assisted death of a patient on the basis that her life was over since she was blind and a wheelchair user. Well, I also can't see and I use a wheelchair. How many people have been infected with that destructive image? I'm angry and insulted."

A young man had developed a neurological condition that was slowly limiting his motor abilities. He was hurt when a parish leader suggested he no longer come to services since his condition made others uncomfortable. He left the church, as did his wife and children.

An elderly parishioner told herself that all she needed to participate more fully in Mass was a little more light on the pages, and possibly a slightly larger print font. Early morning Mass had been an important event for her, but it was becoming hard to follow now and sometimes she got a little confused. Maybe she really was in the way now that she'd slowed down and had a little trouble hearing. She wouldn't bother them anymore. She could just pray her rosary alone. God would understand.

Intertwined Stereotypes and Life Issues

The judgment "I'd rather be dead than disabled" is a painful reminder of the low value placed upon the lives of those who live with disabilities. And this troublesome refrain collides with our Catholic views about the sanctity of life. For those words can fuel the outmoded fears about unwanted dependency which are often associated with infirmities and move people to choose death over inconvenient life. Whether a given eugenics campaign endorses euthanasia, infanticide, or abortion, those less devoted to our belief in the sanctity of life are easy prey to each retelling of those ancient and no longer appropriate terrors of dependency which stalked the nightmares of our ancestors. The assaults upon life move forward because so few of us are knowledgeable or comfortable enough to speak out positively about the power of the powerless and the potential of those who are disabled.

Unfortunately, even the most pious among us may reinforce this negative image of disability by gratefully murmuring, "There but for the grace of God go I." Such statements would seem to imply that those less fortunate have somehow slipped outside the loving embrace of God's concern and grace.

We currently face a new and insidious justification for the death of unborn babies, based on the need to relieve the pain and suffering of those who are "afflicted" with certain disabilities. While we may wish to promote research and development of new procedures that will prolong the productive lives of those who develop disabilities, many choose to ignore the moral implications of fetal tissue research experimentation in an attempt to avoid the dependency associated with certain impairments. Here again, the fear of disabilities fuels the campaigns to promote death.

As we anticipate the frailties of life, we could look for positive alternatives to death, creating environments that encourage greater interaction and care. Too often we fail to see our elders as having sufficient value to merit rehabilitation or independent living services.

A utilitarian view of life, whether held by advocates of death or those with no strong position on life issues, prevents us from thinking creatively about options and reinforces negative views of disabilities at all stages of life. And when options and new experiences are blocked for those living with disabilities, depression often follows. Depressed individuals are less motivated to continue the struggles of life. The campaigns to kill these individuals can be justified when we, as members of the community, fail to recognize that situational and clinical depressions follow all life-altering threats to our status quo. If a non-disabled friend becomes suicidal, we rush them toward psychiatric assistance, and our psychiatrists are well-prepared to deal with such "normal" patients. But when that situational depression is based upon loss of a function we consider essential, we join in the fear of our shared fragility and tend to reinforce the spiral toward greater depression. Either verbalized or unspoken, the phrase "I'd rather be dead than disabled" reinforces the impression that there is no better solution than death. Those of us with a commitment to the sanctity of life can benefit from a closer examination of the paradigms and strategies that have been developing within the community of disability concerns.

A Bit of Recent History

A few short decades ago, people who suffered from traumas that left them with limited functional abilities were not expected to live long. Infants with various deficiencies were not expected to survive to adulthood. Infections and other medical complications "mercifully" terminated the lives of those designated as incurables and invalids.

But skills learned in recent wars have brought fresh hope. Doctors have learned to salvage maimed bodies, and rehabilitation strategies have evolved that allowed those who had lost one or more functions to find and practice alternative methods to accomplish essential tasks and master assorted skills. Specialists in both medical science and rehabilitation have made it possible to integrate children and adults with disabilities into a society that too seldom was prepared to welcome them. Ancient fears of dependency and loss of independence have been slow in fading in spite of increased evidence that individuals with disabilities may continue to be contributing and productive members of society.

Concepts That Support Life

As people with disabilities searched for a common voice, they developed new concepts and paradigms that could better explain their sense of pride and self worth. They recognized the joy of living in spite of their assorted physiological glitches and determined to find ways to fulfill their potential.

People with disabilities campaigned against being approached with pity, noting that it blocks the message of inclusion. Pity limits, shames, and never elevates the one toward whom it is directed, and it reinforces the fears and depressions that accompany the development of impairments. It is an unwanted projection of society's fear and discomfort. Appreciation of each individual's abilities, respectful compassion, and mutual recognition of our shared fragility must replace pity if we are to become united as people of God.

An essential shift in societal attitudes occurred when the medical model, which sees those with impairments as patients whose needs must be met in special ways, was replaced by a political socio-economic alternative in which the environment is conceptualized as a critical handicapping factor. When environments are created that welcome those with disabilities, there is less need to fear the inevitability of loss of function. This new view was an essential prelude to the drafting of the civil rights protections of the Americans with Disabilities Act. There was growing recognition that individuals with disabilities must be considered members of a minority, too long subjected to discrimination and segregation.

Another life-affirming tool grew from a new definition. "Disabilities" are the normal, expected, and anticipated outcome of the risks, strains, and stresses of the living process itself. Therefore, disability cannot be seen as solely an individual tragedy but instead becomes an expectation within any community. When universal design is used in creating environments that are broadly welcoming, disabilities lose their capacity to terrorize.

The positive messages of our faith offer another conceptual shift. While the symbol of the cross is essential to our Catholic faith, we are the Easter people who look beyond Calvary to the sunrise of that glorious dawn when the heavy stone blocking our view of his power and grace was rolled away. The old association of disabilities with the suffering Christ can be expanded to include the miracles of rehabilitation as small reminders of his Resurrection. When the human spirit prevails regardless of the fragility of its earthen vessel, we glimpse our powerful relationship with the Body of Christ.

A final conceptual view of disabilities may be particularly effective in countering the death campaigns. This view suggests human vulnerability and disabilities have some social benefits.

The Merit of Our Shared Vulnerability

Our shared vulnerability, which is rooted in our gene codes, may be the catalyst that effectively counters our tendency toward alienation and selfish preoccupation, bringing us together in positive ways. Disabilities may well be the glue that can hold us together as community and Church with the knowledge that we need each other and our Lord. Without awareness of our mutual interdependence we may mistake our temporary personal independence as the source of our power.

Vulnerability reinforces behaviors that strengthen the threads of our social fabric, for it is through mutual aid that interaction between people is maintained. Without the evidence of our own weakness and fragility, many of us would ignore the message of unity. When Christ called upon us to seek the safety of the fold, the message was of our need, not our ability to thrive in isolation. Recognition of our interdependence weaves the strongest social fabric. Those of us, whether adults or children, who need others, who depend on interaction and love, serve as catalysts for unity in a society filled with estrangement and alienation. Those of us with such "imperfections" may, in fact, force relationships and community on a society in sore need of such therapy.

Those who preach euthanasia must minimize our human interdependency or their campaigns will fail. They must remind us of our outrage that we grow older and more limited each day. Life's stresses can take little nibbles at our physiology but can't destroy our souls. Only our silent agreement that death really is preferable to life with a disability allows our sense of morality to shrivel and wither.

Within this context, the frantic hope to avoid naturally occurring disabilities would appear to sprout from the same seeds that yield a caustic crop of alienation and disharmony. If we care only for ourselves, our children will not value themselves and will find their own destruction in our streets. If we don't care enough to find the resources to enable our weakest members to find ways to live productively, then we face our own dependent stagnation or death when we fail to fit the utilitarian standards we have embraced.

The point where human life ceases to be valued and becomes a "thing" to be destroyed or used by others who deem themselves more "worthy" marks that point where morality prevails or dies. And when medical professionals or political systems encourage the harvesting of one life to nurture another or allow one life to be sacrificed for the convenience of another, we lose a sense of the uniqueness of each life. By devaluing any human life, we will have fostered the alienation which stalks our society. Surely these risks merit our most prayerful contemplation.

At the same time, whenever anyone feels needed and essential to another, the threads of interaction are reinforced and the fabric that holds us together as Church and society is woven more richly and powerfully strengthened.

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The following is the complete text of the paper delivered by Mary Jane Owen to the Seventh International Conference of the Pontifical Council for Pastoral Care to Health Care Workers in Vatican City on November 20, 1992.

The Wisdom of Human Vulnerability ~ Disability: The Tie Which Binds

A learned man of God, John Cardinal O'Connor, offered this guidance: speak from the heart of the experiencing of human vulnerability and wear your disabilities like a mantle about your shoulders.

For two decades I have been a participant observer, contemplating our mutual fragility and struggling to comprehend the foolishness of God's insistence on placing our precious souls into such fragile containers. Our efforts to avoid recognition of our frailty speaks loudly of our sense God's choice was an oversight and certainly imprudent. The never-ending search for the Fountain of Eternal Youth tells the story of our dismay. We find it difficult to accept the reality that we face eventual physiological disintegration.

This paper suggests that some of the conceptual lenses through which we have traditionally viewed our own and other's vulnerabilities distort and frighten us. The old prescriptions blur our vision of our need to foster interdependency. There is little need for the fear which stalked our ancestors' nightmares. Current medical and rehabilitation technology and techniques can assist our brothers and sisters; sons and daughters; husbands and wives; mothers and fathers to remain interactive and involved with those whom they love and who love them as various functions diminish or are lost. I do not propose an end to our efforts to reduce suffering, only that we approach those challenges with deepened awareness that vulner-ability may be an essential component in God's plan for us.

The judgement, "I'd rather be dead than disabled," is a painful reminder of the low value placed upon our lives. And this troublesome refrain collides with our views about the sanctity of life. For it fuels those outmoded fears about unwanted depen-dency which are associated with "infirmities" and moves people to choose death over inconvenient life. Whether a given eugenics campaign endorses euthanasia, infanticide or amnio-centesis and abortion, potential colleagues are easy prey to each retelling of the ancient and no longer appropriate terror. The assaults upon life move forward because so few of us are knowledgeable or comfortable enough to speak out positively about the power of the powerless and the potential of those who are disabled.

And the pious reinforce this negativity as they mutter, "There, but for the grace of God, go I," failing to recognize the verdict they have leveled against those who live with disabilities and who may still be well within the circle of God's grace and love.

Against this sketchy background, let us quickly examine a few conceptual lenses which will allow us to glimpse the potential of those with disabilities:

1. A shifting paradigm replaces the medical model, which sees those with impairments as "patients" whose needs must be met in "special" ways, with a political socio-economic alternative which conceptualizes the environment as the handicapping factor.

2. A new definition asserts: "Disabilities" are the normal and anticipated outcome of the risks, strains and stresses of the living process itself. Therefore, the condition ceases to be merely an individual tragedy and becomes an expectation within any community.

3. The symbol of the Cross is essential to

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our Faith, but we are the Easter people who look beyond Calvary to the sunrise of that glorious dawn when the heavy stone blocking our view of His power and grace was rolled away. The old association of disabilities with the suffering Christ can be expanded to include the miracles of rehabilitation as small reminders of His Resurrection. Thus we confirm we are a part of His Body and our souls strive to prove His power.

4. Each time words of pity target those with disabilities the message of inclusion is blunted. Pity limits, shames and never elevates the one toward whom it is directed. It is an unwanted projection of society's fear and discomfort. Respectful compassion and mutual recognition of our shared fragility must replace it if we are to become united as people of God.

5. The fifth lens is pivotal if we are to justify the challenge of this new orientation, for a new prescription calls for a lens which can focus on the power of human vulnerability. Until we recognize this trait as valuable to the health of any organization, we will lack motivation to alter our current patterns of exclusion and separateness.

Our vulnerability, which has been encoded into our gene pool, is the catalyst which brings us into community and church with renewed recognition that we need each other and our Lord. When God tied the gift of life to the trait of vulnerability, He may have given us the only incentive which could counter our tendency toward disregard of the rights and value of others. When we see ourselves in our peers, we are joined in a bond which comes from the heart. When we are unaware of or deny our interconnectedness, we move about functioning as if our souls had been placed in high impact plastic bodies. We tend to become alienated and solitary, mistaking independence as the source of power. We take a "Kleenex" approach toward life, justifying its disposal when it becomes less than perfect.

It is through synergy and mutual aid that communities are built and maintained. Without the evidence of our own weakness and fragility, many of us would ignore the message of unity and interaction. When Christ called upon us to seek the safety of the fold, the message was of our need, not our ability to thrive in isolation.

On a personal level, I saw no value in vulnerability when it began to creep upon me in 1972. I was focused on a professorial title. Everything of importance seemed tied to my visual acuity and photographic memory. I was a brilliant scholar and now my opportunities were slipping away as my vision faded.

An academic colleague tried to comfort me with these words, "When Caesar Chavez goes out to organize the migrant farm workers, he always asks for a match although he doesn't smoke." Such a simple request pricked the surface of that bubble of tension which separates us from each other. A modest need was the "excuse" for starting a serious dialogue.

I heard no comfort in my friend's words. He was telling me that as a blind woman I'd have to go through life asking for help. That image had nothing to do with my view of power and autonomy. Not surprisingly, I lapsed into self pity, "I'd rather be dead than have to go around asking for help all the time!" But God had many more lessons for me than I could have imagined.

And so one day I had to travel alone to another city. I moved through the doorway into the huge bus terminal barely touching the floor with my white cane. I hoped no one would notice I was blind. The trip to the counter was uneventful but then I had to utter the dreaded words. The result was worse than I'd imagined. The man pulled down the microphone and out boomed my embarrassment: "Will someone please help this blind woman catch the bus to Sacramento?"

The cavernous space had seemed oddly silent. One knew there were people waiting on the hard benches but no one spoke. Then suddenly all that changed. "Here, let me help you to a seat," someone said. And as we passed the previously silent bodies, there was a buzz of chatter. "I'm going to Placerville to see my grandchildren." And I was greeted with the news of a young man's trip to Quincy to check out the college there. The room which seconds before had been like a tomb of anonymity was transformed into a gathering place for friendly travellers, all sharing a few words to ease the boredom of their wait on a journey to somewhere else.

That was not the final lesson. I was a slow learner but with each venture realization grew. When I gave myself permission to ask for help, those around me were given the "excuse" they needed to feel needed. Amazing, but my vulnerabilities were the catalyst which gave others permission to unite: to behave as community.

"How come you know so many people?" "Because I have to move out each day, trusting that minor miracles of happenstance will occur again today. When depending upon chance encounters allows for one's freedom to come and go, there are few strangers in one's path."

When people move out into their world in such a manner, they are catalysts and confirmations of mutual need. Can there be any doubt we need that fragility which can unite us? For, as a society, we are sickened by alienation and solitude. But until we throw away some of the dysfunctional myths and fears, we will not profit from the richness of God's gift.

Too many individuals with disabilities have awaited their turn to worship and to serve their Lord. Too often the Good News has been proclaimed behind barriers we could not overcome and our potential contributions have gone unnoticed. Upon signing the Americans with Disabilities Act, our President told the thousands assembled on the White House lawn that this law was a sledgehammer with which to smash the ancient walls which had blocked 43 million people from fulfilling their dreams and offering their gifts to the nation. That wall of prejudice and fear extends around the globe, separating and segregating.

A united resolve to smash the old conceptual lenses which blurred our vision of the power of human vulnerability can destroy the old prejudices. We must constantly remind ourselves that God's gift of life is placed in fragile earthen vessels to a powerful purpose. We have only to recognize and celebrate that reality and it will free us from past fears.

For it is our common recognition of interdependency which weaves the threads of our societies together. Each time one of us feels needed and essential to another, the threads of that interaction are reinforced and the fabric which holds us together as Church and as society is powerfully strengthened.

There is wisdom in vulnerability and it will bind us together powerfully, if we will only look at the reality with fresh vision.

May God bless our mutual crusade.

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"Who Causes the Blind to See": disability and quality of religious life

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ABSTRACT *Persons with physical or mental disabilities often turn to religious institutions for comfort and belonging. They are not, however, always openly welcomed into religious circles. Many churches and synagogues fail to make the necessary accommodations for parishioners with disabilities and some show covert signs of hostility towards them. Possible reasons for this exclusion are examined, theorising that they stem from the most ancient of beliefs about the nature of disability and its relationship to God. Sources within the Jewish and Christian faiths are examined and it is hypothesised that there are four central views inherent in these religions that act as barriers to those with disabilities. These beliefs must be challenged so that all may find fulfillment and inclusion within their religious faiths. Religious leaders and followers must also acknowledge and redress the fact that such beliefs have contributed to the establishment of disability and an oppressed political minority within Western society.*

> And the Lord spoke unto Moses saying: Speak unto Aaron saying: Whosoever be of thy seed throughout their generations that hath a blemish, let him not approach to offer the bread of his God . . . A blind man, or a lame or he who hath anything maimed or anything too long . . . crook-backed or dwarf . . . he shall not go to the veil nor go nigh unto the altar because he hath a blemish; that he profane not My Holy places. (Leviticus, 21:17–24)

Introduction

Quality of life for many individuals typically revolves around religion and its associated organisations. Religious institutions offer meaning and comfort to many who seek guidance and support in a world seen as troubling and confusing (McAfee, 1988). Community is often formed out of religious experiences and the commonalities which draw individuals together to form a cohesive and supportive group (Hoffman, 1969). Whatever level of religious commitment and involvement the

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individual chooses, most participants feel that religion is central to the make-up of their quality of life (Park, 1975).

Those with disabilities too, often express an interest in and find fulfillment from religion. Scuccimarra (1990) found that after television and movie viewing, attendance at church ranked as one of the most favoured activities of young persons with disabilities. Similarly, Schalock *et al.* (1981) studied the adjustment of adults with developmental disabilities who had been placed into independent living situations. Data from this study revealed that churches were the most frequently accessed community facilities, coming before restaurants, launderettes and grocery stores.

Although many persons with disabilities feel connected to their religious communities, they are not always welcome participants (Bryant, 1993). An early study of church involvement among individuals with developmental delays by Baller (1936) found that although attendance rates among the population were quite high (at more than 50%), participation in church related activities and responsibilities were severely restricted. Later studies found that while attendance rates among persons with disabilities remained high, memberships in choirs and clubs were substantially lower (Kregel *et al.*, 1986; Wilhite *et al.*, 1989).

Studies of clergy and their relationship to persons with disabilities highlight the fact that services and accommodations for the population are often severely restricted. Heifitz & Franklin (1982) found that although clergy felt compassion for those with disabilities, their knowledge of services available to them within the religious community was limited and their ability to modify religious education or to accommodate their services was low. In a comprehensive study of clergy and their accommodation of persons with disabilities, Riordan & Vasa (1991) found similar results. Access to those with physical challenges was reported by less than half of the congregations. Forty-four per cent of clergy reported little or no special religious classes for those with developmental delays. The authors conclude that many clergy are isolated from congregational members with impairments. Willing, though largely unable to assist those with disabilities, clergy are somewhat unrealistic in their ability to provide special services, preparation for rites of passage events and general religious functioning.

Thus, it is clear that religious communities are not making the necessary accommodations for those with disabilities. This fact seems to conflict with the general perception of religious institutions as havens for all peoples. The root of the apparent alienation of individuals with disabilities by religion may lie in the ancient belief systems of the Judeo-Christian theology which views disability in a highly negative manner. In fact, it can be argued that the views of Western religious institutions have helped to create the social construct of disability as a political state of oppression and have been instrumental in maintaining its power and pervasive nature (Barnes, 1995). Such a state goes well beyond the physical charcteristics which differentiate those with disabilities from the general population (Roth, 1983) and it can be contended that the label of disability has become a minority grouping and not merely a medical definition (Hahn, 1988, 1993, 1994). This, in turn, has lead to the exclusion of those with disabilities from many elements of political and social power and has amplified the dependence of the population on a society which treats them with pity, disdain or fear (Abberley, 1987).

An examination of this theology finds that attitudes toward those with disabilities can be categorised under four general headings, which together can be seen to form the basis of many beliefs within organized Western religion. These are: disability as sign of punishment or evil incarnation; disability as challenge to divine perfection; disability as object of pity and charity; and disability as incompetence and exemption from religious practice. Taken together, these attitudes form a theological barrier that may be obstructing the rapid and complete integration of persons with disabilities on the part of religious institutions and may serve to deny the quality of life which so many seek. They may also provide insight into many of the assumptions and prejudices which operate in the broader secular society, as these have been heavily influenced by religious thought and doctrine.

Disability as a Sign of Punishment, Evil Incarnation and Disease

Western religious views on disability were likely influenced by early pagan attitudes towards physical or psychological difference. As Kiev (1964) notes in his examination of primal religious thought, non-normative states of being such as disability or disease, were seen as intrusions into the soul or loss of spirit, induced by witchcraft or violation of taboos. It is likely that later biblical sources took these attitudes and modified them in a monotheistic context, utilising them as a means to ensure adherence to law and maintenance of fear and loyalty to an unseen deity.

Henderson & Bryan (1984) state that biblical precepts continually make the connection between disability and evil, and physical ability with virtue and cleanliness. Historically, this attitude has left persons with disabilities vulnerable to societal practices of isolation, sterilisation and euthanisation in the name of religious purity. While these practices have (for the most part) ended in Western societies, the myth of disability as evil incarnation persists.

Religious art and writing have furthered this association by consistently portraying divinity and its associated images (angels, saints, etc.) as able-bodied. Conversely, Henderson & Bryan (1984) cite the findings of a religiously themed literature review, and note that disability has been linked to sinfulness, dirt and evil.

Biblical text abounds with images of disability as evil. Weinberg & Sebian (1980) cite many of these references in their research into Bible and disability. They note the fact that disability is often linked with diseases brought on by the wrath of God. The punishment of evil through physical torment takes several forms in biblical narrative, many of them closely linked with physical disability. The Old Testament, for example, states that if humans are immoral they will be blinded by God (Deuteronomy 27:27). In the books of Exodus, Numbers and Deuteronomy, the people of Israel are repeatedly punished for their sinful ways through physical disability. A discussion of ritual purity (Numbers 5) notes that blindness, leprosy and other disabling diseases are punishments for blasphemous behavior. In Exodus (20:5) God tells Moses that retribution for sin will be inflicted on the offspring of the sinners for many generations. In the book of Samuel, the prophet Nathan admonishes King David for his sins and though he is repentant, he is punished through his new-born child, who is condemned to death.

Contemporary Jewish prayer includes passages such as 'who causes the lame to walk', 'who gives sight to the blind' and 'who has created me with all functioning organs and limbs' (Silverman, 1956, pp. 103–105). From this, it could be argued that in the minds of many Jewish worshippers, God is powerful over disability and disease, and the condition is not to be accepted as natural or normal.

The New Testament continues in this tradition. Weinberg & Sebastian (1980) note that in the book of John (5:14), the people are told that they will recover perfect health if they cease their evil ways. The book of Matthew (9:2) brings the most striking example of the connection between disability and sin, as Jesus cures a man with palsy after declaring that his sins are forgiven. As Barnes (1995) states, later leaders of the developing church maintained and promulgated this negative connotation. 'St. Augustine, for example, the man credited with bringing Christianity to mainland Britain, perceived impairment as "a punishment for the fall of Adam and other sins". Martin Luther, the Protestant reformer, was an enthusiastic advocate of infanticide for disabled infants because they were the Devil's children' (p. 12).

Some modern churches have been active in perpetuating the connection between evil and disability, and God's role in the healing process. Many so-called church "faith healers" have demonstrated the power of religion and forgiveness by seemingly causing those who use assitive mobility devices to walk without them, restoring sight to the visually impaired and hearing to those with deafness. The message sent by these acts is clear, disability contains in it elements of disease and evil presence. Faith in God restores good health and can overcome the imperfection of disability. Disability is, therefore, seen as an abomination, an act of punishment or evil that is an unwelcome addition to the lives of the faithful.

Disability as a challenge to Divine Perfection

One of the basic theological underpinnings of the Judeo-Christian religious faiths is the belief in the perfection of divinity and the creation brought about by the Divine. A child born with characteristics which deviate from the norm would appear to seriously challenge this notion. In an article examining the theological difficulties brought on by the existence of those with developmental delays, Adams (1984) notes the theological axiom which states that if God is both omnipotent and essentially good, then all that is created by God would be healthy and complete. Thus, the existence of imperfection in creation is not only a challenge to the notion of God's perfection, but of God's basic goodness as well.

Themes of perfection and ideal forms abound in biblical sources. In describing the specifications for ritual sacrifice, the Old Testament notes the fact that animals with physical defects are not to be used for this purpose (Numbers 28:9). When outlining the qualifications for the selection of the high priest, the Bible states that a candidate (Leviticus 21:17–24) must not be disabled or imperfect in any way. Though it may be uncomfortable for modern society to acknowledge, the Bible is clear in its message that perfection and beauty should surround things religious and that imperfection is to be rejected. The presence of those with disabilities then, presents a constant and serious challenge to the notion that divinity and creation are perfect. In addition, it seemingly subverts the divine desire to be surrounded by beauty and wholeness.

Disability as Object of Pity and Charity

Though disability may be seen in religion as evil in nature, there is great pity given to those who are sinful and those who are products of God's punishment. Additionally, for those who reject the notion that disability is evil, but given to humanity as a means of bringing about justice and charity (Moskop, 1984), persons with a disability are seen as vehicles for the able-bodied believer to practice acts of kindness and good.

Religion does appear to pity those with a disability. Henderson & Bryan (1984) cite an example from the Talmud ordering the recitation of a special prayer when passing an individual with obvious visual impairment. The Bible instructs the people to take pity on those who are challenged and to care for them with charity and acts of loving kindness (Weinberg & Sebastian, 1980). Historically, religious institutions were the first (and often only) providers of care for persons with disabilities. Religious orders have traditionally offered medical attention to those with impairments, provided schooling and have led the way in raising charitable funds to ease the suffering of those not able-bodied.

The difficulty in viewing persons with a disability as objects of pity and charity is two-fold. First, by being classified as 'disabled', persons with an impairment become objectified, thus losing a sense of individuality and basic humanity. A 'disabled' person is no longer simply a member of a congregation requiring assistance in order to function as an equal participant. Instead, they become a project, a vehicle for others to fulfill their acts of kindness. Their existence as a person is thus subservient to their disability.

Secondly, by becoming objects of pity and charity, persons with a disability become a charitable responsibility. Their needs are not necessarily seen as rights, but as privileges of a society that can afford to care for them. This belief has resulted in a structure of services and accommodations for those with disabling conditions that depend solely on the whim of the congregation or society. They are not determined by an overriding belief in the rights of all individuals to fair access to religious and public services and membership in communal institutions. Evidence of this can be seen in the inconsistency of services and accommodation for persons with a disability in religious communities (Hawkins-Sheppard, 1984; Fewell, 1986).

Religious attitudes have affected services to persons with disabilities in the secular community as well. Government assistance and accommodation programmes have often been funded based on charity and pity, and not on human rights. This type of attitude in the education and community services branches of government necessitated the passing of legislation in many countries to ensure that the rights of those with disabilities were entrenched, and that service would be guaranteed and not merely given as a nicety based on societal feelings of compassion and guilt.

An example of how this attitude pervades in contemporary religious political thought can be seen in the personification of persons with disabilities in debate over abortion and physician-assisted suicide. In the literature written to support right-wing Christian efforts for greater control over medical decisions, persons with disabilities are piteously characterised as 'beautiful' (Moore, 1995), unable to defend themselves against liberal attempts at euthanesia (Lawrenson, 1996) and not yet capable of recognising the issues which are central to their own survival (Moore, 1995). Such rhetoric largely fails to acknowledge the existence of self-advocacy groups, a majority of whom have not joined forces with the Christian-right. Statements which claim to favour great self-determination for persons with disabilities seem to be philosophically opposed by the greater goal of the so called 'pro-life' movements, as it clearly advocates less individual freedom and choice. While the existence of successful persons with disabilities is used as evidence to bolster support for a ban on abortion and physician-assisted suicide (Dieleman, 1995), the use of the population as objects of pity does little to support rights and freedoms or to shatter long-held stereotypes.

Disability as Incompetence and Exemption from Religious Practice

In the Jewish legal code, persons with a disability are often seen as legally subnormal and incompetent. Legally, they are placed on the same level as minors and are prohibited or exempt from fulfilling many community functions. The Talmud notes the fact that persons with a developmental delay (known in ancient Hebrew as *Shoteh*) or a hearing impairment (known in ancient Hebrew as *Heresh*) cannot act as agents or principals in legal transactions of ownership transfers (Talmud Gittim 23A), nor can they normally make gifts of property (Maimonides, Mishneh Torah). Other references to those with a disability state that they cannot act as judges or witnesses in Jewish legal courts (Talmudf Sanhedrin 34B). Exemptions in the area of worship prohibit persons with an impairment or disability from reciting certain prayers (Talmud Megillah 4:6), leading prayer services (Havat Yair 176), or being called to the public reading of the Bible or *Torah* (Shulhan Aruch, Orah Hayim 53:14).

The implications of classifying those with a disability in this category of exemption (or prohibition) are far-reaching. As non-functioning members of the religious community, persons with a disability are incapable of full participation in the rituals of prayer and life-cycle events such as *Bar-Mitzvah* and marriage. To be certain, these laws were not created out of malice or overt hostility and may have, in fact, arisen out of a desire to protect those deemed 'incompetent'. These laws reflect a time when persons with disabilities were not educated, and often lacked the ability to communicate and relate to others. Taken together with the previously noted attitudes toward disability, and the lack of information on the nature and treatment of the conditions surrounding disability, the strictness of these laws is more easily understood. Nonetheless, these laws clearly place persons with disabilities in a position of inferiority, incapacity and inequality. They also contribute to the isolation, powerlessness and poverty of a sub-group of community members, a problem which remains endemic to contemporary Western society.

Today, there is a much more lenient attitude taken toward the inclusion of persons with disabilities, though their rights have certainly not been entrenched in Jewish law and practice. The modern rabbi is held responsible for categorising an individual into the realm of the exempt and can, in effect, decide whether to grant the right of full membership within the religious community. An informal survey of some six Canadian rabbis (representing all of the major branches of Jewish practice), revealed that the majority would favor some form of limited communal participation for those with a developmental delay. None would state categorically that individuals would be given full access to synagogue participation and life cycle events. Most reported minimal participation and attendance on the part of those with disabilities in their synagogues.

While the Catholic and United Churches do not appear to have codified the status of persons with disabilities (as is the case in Jewish law), they too place great emphasis on the decision of the individual priest or minister. An informal interview with a member of the Catholic Archdiocese of Toronto revealed that the receipt of the sacraments, confirmation and marriage would only be allowed to persons with a developmental delay on the advice of the individual parish priest. Anecdotal information provided by those who have worked within the church community, or who are themselves physically challenged, suggests that, in some cases, persons with physical impairments have had difficulty obtaining ordination or positions of leadership within the church community.

Changing the Prevailing Custom

The above examples serve to highlight the fact that persons with disabilities have been historically relegated to the status of *persona non grata* within religious institutions. With changes in public policy over the past two decades and the resulting move towards deinstitutionalisation, religious organisations have been receiving growing numbers of persons with disabilities in their communities. The influx of parishioners with disabilities has forced Western religion to confront its ancient prejudices and begin the process of providing this sector of the community with meaningful religious experience and affiliation. Additionally, with the development of the Disability Movement, the voices of those worshippers with impairments (as well as their advocates and supporters) calling for greater access to all public institutions, have added to the pressure placed on religious institutions to revisit their policies and attitudes which have for so long denied many the right to a normalized state of existence (Oliver & Zarb, 1989; Shakespeare, 1993).

This process, though slow in its evolution, is nonetheless taking shape. Adams (1984) presents a compelling theological argument countering the notion that disability presents a challenge to the belief in the perfection of divinity and creation. He states that the plans of an omnipotent God do not necessarily have to be revealed to humanity and may, in fact, be beyond human understanding. The existence of a parallel world of perfection, or the lack of perfection in creation are possibilities which are logical and feasible within a theological framework, and yet do not necessarily challenge the notion of divine goodness and perfection.

In a letter to religious leaders and worshippers, Ellis (1984) calls for the opening of church and synagogue doors and minds. Ellis (a member of the clergy) states that there is much to be done to change attitudes and provide services to persons with disabilities. Rabbi Schneerson, the late spiritual leader of the Lubavitch Hasidic sect, stated in an address to his followers in 1978, that all children, regardless of the labels placed on them by professionals or developmental expectation, should be entitled to full acceptance within the community. All, in his opinion, should be afforded the right to an education that is realistic in scope yet hopeful and progress-minded in philosophy.

These pronouncements notwithstanding, Hawkins-Sheppard (1984) notes that religious education has lagged behind other educational institutions in its adaptation of materials and programmes to suit the needs of students with disabilities. The author provides an extensive bibliography of materials, programmes and curricula available for the absorption of pupils with disabilities into the religious educational classroom. Despite the availability of such materials, the author states that much of the progress being made is occurring in an informal manner. Religious institutions are relying not on specially trained experts and professionally prepared materials, but on the creativity and instinct of lay-leaders and teachers.

Some religious communities are seeking, in an organised and professional manner, to reach out to the population of persons with disabilities and to provide them with specialised religious programmes. The National Organisation on Disability has produced an inter-faith manual entitled *That All May Worship* (Davie & Thornburgh, 1992), designed to raise awareness among faith communities and enhance access to their facilities. The National Catholic Office for Persons With Disabilities, distributes a videotape entitled *We Are All One Flock* (1990), which encourages congregations to allow for the full participation of those with disabilities in religious life. It contains a statement in support of such integration from the Association of American Bishops. Goodman (1993), in an article entitled *The Disabled in the Jewish Community*, presents a plan for a two-pronged approach to complete integration, where access and attitudes are adjusted so as to begin the process of redress such that synagogues may be open to all who wish to participate.

The Reena Foundation, a Jewish organisation in the Toronto, Canada area for the employment, housing and recreation of adults with developmental delays, employs a professional who serves as a religious specialist. In addition to co-ordinating and producing educational materials for the clients of Reena group homes, this professional serves as a link between the community and clients, working for the complete integration of the population in various religious community functions. Other Jewish, Roman Catholic and United Church officials have noted the fact that similar professionals or lay leaders function in various faith communities.

This though, is the exception rather than the rule. As the preceding examples have demonstrated, the bias against the population of persons with disabilities runs deeply within the Judeo-Christian faiths, making progress difficult and painfully slow. Those with disabilities have won many legal and moral battles in their struggle to be integrated into general secular society. Because of the strict separation of church and state, however, legal progress in the religious domain is almost impossible. This means that persons with a disability and their advocates must appeal to religious individuals and institutions to accept and integrate them fully into their congregations. It is sadly ironic that the institutions which help shape the morality of humanity, which preach acceptance and love and which have traditionally assisted those with disabilities, have been so slow to reconcile old beliefs and begin the process of complete integration.

Conclusions

Religious institutions in the Western world are being forced to confront many of the prejudices and beliefs which have allowed for the creation of oppressed minorities within the wider societal structure. It is becoming increasingly clear to scholars and activists that disability must be seen as a social construct, resulting in the relegation of persons with disabilities to the status of an underprivileged minority (Hahn, 1988, 1993, 1994). Negative attutides towards persons with disabilities have given rise to intolerable and untenable conditions for many, both within the church or synagogue and in the broader social context. These attitudes are difficult to rend from the fabric of religious beliefs and there are many who feel that doing so would ultimately serve to undermine the basic structure and makeup of religious traditions. As with attitudes which discriminate on the basis of race, gender and sexual orientation, the views held by Western religion towards disability seem to lie deep within the core of its basic beliefs.

It is the challenge of all those who value religion in its many forms, to see that there are deeper core beliefs which supersede exclusionary and oppressive dogma, and which, in fact, form the nucleic bedrock of all faiths. These are the ideals of inclusion and acceptance, the glorification of divine creation in its many forms and a striving for the betterment of humanity. It is this set of deeper-core values which not only allow religion to cast off its negative prejudices, but compel it to do so. An understanding of the negative attitude taken towards disability and an examination of their historical, political, psychological, sociological and economic etiology is warranted as a first step toward discovering the means of liberating religion from such destructive beliefs.

If it can succeed in achieving this delicate and precarious task, then religion may be in a more advantageous position to continue playing a central and emergent role in the lifestyle of modern society. If not, it runs the risk of becoming mired in its oppressive and outdated mode of rationalisation and may itself fall victim to a tide of rejection and isolation brought on by the new political and social realities of contemporary Western civilisation. Such adherence to dogma will most certainly continue to foster a climate of anger, dissention and conflict, which in and of itself seems to run contrary to the goals of religious tolerance and community building.

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Anna Sobolewska

The Masks of God

> ..."Get to know suffering, though there is nothing to know; reject the cause of suffering, though there is nothing to reject; cultivate everything that helps to interrupt suffering, though there is nothing to cultivate."
>
> (Dalai Lama)

Contra Theodicy

Two small books recently appeared — two testimonials of parents of incurably ill children: Harold S. Kushner's *When Bad Things Happen to Good People* (1981) and Mary Craig's *Blessings* (1992). The author of *Blessings* is the mother of two handicapped children; one of her sons has Downs syndrome, the other was born with the Höhler syndrome, a genetic defect called "gargoylism" or "monsterism" (the very name is frightening). Mary Craig made friends with several Poles from the Sue Ryder Foundation. (Sue Ryder is an Englishwoman who after the war cared for the victims of concentration camps.) These contacts helped Mary Craig to overcome the feeling of isolation and faultless injury. Both books are something more than private documents of the struggle with despair; they are small philosophical treatises about fate, suffering, faith.

Rabbi Kushner and Mary Craig subject to revision the traditional idea of Providence. Instead of theodicy — justification of a good God in the face of human suffering — they propose solidarity of fellow sufferers. The world according to Kushner is not the theater of Providence, a force rewarding or punishing man, but the field of action of morally blind nature, which "mills" human destinies according to the mechanical laws of necessity and chance. We all are (or will be) the innocent victims of this force, like Job was. Job was not in the least responsible for the evils which fell upon him. Neither were God or Satan their authors. In Kushner's interpretation the Book of Job is a picture of consciousness incapable of transcending the magic belief that the vicissitudes of faith are a punishment of reward of Providence. No one has the right to feel either its darling of victim.

Rabbi Kushner writes with irony that in many European languages the greatest cataclysms of nature are called "acts of God" or "force majeure" ("higher power"). This terminology conceals the measure of our false consciousness, which reduces God to the dimensions of a vindictive demon. People "must establish insurance companies to protect themselves against acts of God!" Is God an experimenting director of human destiny, like the hidden demiurge in Krzysztof Kieślowski's "Red," who had to sink an entire ship so that two passengers could meet?

In Kushner's opinion, the vicissitudes of human fate are hardly a manifestation of moral or immoral behavior; they elude human and divine control. At the same time, their sense eludes human consciousness. "Life is not fair. The wrong people get sick, the wrong people become victims of holdups, and the wrong people are killed in wars and in accidents. Some people, seeing the injustice of life, come to the conclusion that God does not exist and that the world is only chaos." Kushner, *When bad things happen to good people.* This pessimistic picture contains the grace of consolation and mutual understanding. "We all deserve a better fate" — Rabbi Kushner consoles his readers. Paradoxically, giving up the idea of God as the dispenser of rewards and punishments is often the only way of rescuing faith.

Other thinkers have pointed out the symbolic or parabolic dimension of human fate. Mircea Eliade treated life, which is replete with victories and defeats, as an initiation scenario, a series or tests on the path to spiritual initiation. What then is our life? An initiation scenario preparing us for "salvation" or "enlightenment" or a sequence of chance happenings? As Rabbi Kushner's understands it, life is more grotesque than tragic; tragedy would require the force of destiny and not the soulless force of a mechanism. At the same time, Kushner requires from his readers heroism and faith in the sense of experiencing absurd happenings. This is a proposal of Stoic or Buddhist proportions, and is not as easy to accept as it appears.

Fortunately, Rabbi Kushner's theology is not consistently pessimistic. For perfect logical consistency of a system often makes it inhuman. According to him, the world is a soulless mechanism when it inflicts wounds on us, but the same world in the aspect of good is divine. That is why Kushner warns against associating illness and lameness with the "will of God," but advises us to see God in the return to health:

> Our question will not be Job's question: "God, why are you doing this to me?," but: "God, you see what is happening to me! Can you help me?" We turn to God not

> to have Him judge or forgive us, not for reward or punishment, but for strength and consolation.

Thus Kushner's theology brings consolation, although the question of evil remains unanswered. Perhaps here on earth the question of evil and suffering has not other solution than a religious one. Philosophical constructions fail. Rabbi Kushner's deliberations about the Book of Job are by no means philosophical or theoretical. In his own home he himself had to cope with the role of Job as the father of a crippled child. His son Aaron was afflicted with a genetic disease causing premature and galloping aging. The boy with the appearance of an old man died in his teens. Rabbi Kushner managed to turn the terrible suffering of a father into a religious experience:

> I deeply believe that Aaron served the work of God not by his sickness or strange appearance (God had no reason to cause this) but by his courage in the face of sickness and the problems presented by his appearance. I know that his courage and the way in which he lived life to the full in spite of his limitations made a profound impression on his friends and schoolmates. I know, for example, that Aaron inspired the people who knew him to fight against their own difficulties with greater hope and courage. For me these are examples of the influence of God on people, so that here, on earth, they would help others who are in need.

Kushner recalls the opposition of necessity and good present in the works of philosophers from Plato to Simone Weil. What is interesting is that the vision of Providence that is consistent with our wishful thinking collapsed not under the blows of anti-clerics but under the pen of religious thinkers like Simone Weil, Thomas Merton and Harold S.

Kushner! It is the parents of handicapped children who often feel the internal compulsion to wrestle with the eternal dilemma of humanity. Instead of closing themselves up in their own existential tragedy, they ask questions about the sources and sense of suffering.

"Christmas which Lasts All Year"

The author of *Blessings* said of her little son with Down syndrome: "Christmas which lasts all year." Life also convinced me that there is no exaggeration in these words, although it is sometimes hard for people to believe this.

In June 1989 my younger daughter Cecylia was born. I remember when I was laying in the hospital, exhausted but happy, with the other mothers impatiently waiting for the first feeding. However, my baby daughter was not brought to me. I was unexpectedly transferred to another room in the septic ward. On the morning of the second day, during the rounds, I was informed that Cecylia probably has Down syndrome. The lady pediatrician asked the question: "Why didn't you have tests done?" This rhetorical question meant so much as that I myself was to blame and that the hospital does not like handicapped children.

I remember well the despair of the next several days. The world seemed bleak and oppressive to me. The cheerful conversations of the happy mothers in the next beds wounded me painfully. My little daughter was a beautiful infant, but in her I painfully recognized the characteristic features of the Down syndrome "mask."

I remember the feeling of dissociation experienced in these first weeks: still not reconciled to the Down syndrome I felt an inner burden, sadness and discomfort, but at the same time with some part of my being I was delighted with the presence of this small, unusual little person, whose coming into the world first shocked the feeling of happiness and then multiplied it. During the first year paradoxical situations took place: when we were alone we took delight in Cecylia, in her first smiles, the progress which she made. Only the visits of some guests, their exceptional tactfulness and gestures of pity reminded us that we were supposed to be unhappy. After a certain time this dark stream of experiences exhausted itself. Breast feeding greatly strengthened our bond.

Ordinary births and caring for a small child introduce something like a state of "emergency" into the life of the family — constant rejoicing. With a small child time becomes more condensed, tense, festive. Guests visiting the home in which a child was born leave their cares on the doorstep. A small child is always exceptional, the only one. It endows us with grace. A shrieking infant is at the same time the archetypal "infant" retaining the traces of its divine origins.

The birth of a handicapped child looks different. Instead of joyous celebration, there is sadness and resignation around such a child. The congratulations of guests resemble condolences. Acquaintances often turn into "friends of Job," who unwillingly wound instead of console. In fact, this is a period of mourning after the miraculous, "ideal" child which was supposed to be born. This period may last an entire lifetime, but this does not have to be so. In the first moment everything that tears us away from our own "I" (prayer, meditation), which is weighed down by the sense of injury, is a big help (for me it was yoga and spiritual help of Swami Chidvilasananda). The period of "mourning" gives way to a joyous bustle. And the child, despite its slanted Down eyes, may become the infant dreamed of during pregnancy.

A normal child quickly ceases to be a "star from heaven" and becomes an ordinary member of the family. The people around it, instead of constantly admiring it, start driving it away. This is registered precisely by language. In some languages the diminutive form is used to express the child's age until the age of four, after which no diminutive is used. It is otherwise for a child with Down syndrome: it always has several "little years." The joyful tension accompanying its progress never ends. In bringing it up we can celebrate without end. Little problems like "eating porridge" do not matter. Many ordinary cares are put to flight, but other, more serious ones take their place. And yet the excess of concern may be counterbalanced by an excess of joy.

All of this counts double: the first smile, the first words and sentences, even the first lies! Every accomplishment is a gift of fortune. To be able to take pleasure in this one must first acknowledge that nothing is owed to us: not health, not success, nor children "with all the necessary qualities." As Janusz Korczak said — a child is not a lottery ticket in the big game of fate. The capacity to experience happiness must be founded on the unsentimental awareness of which Rabbi Kushner wrote. This bitter awareness by no means leads to despair; on the contrary, it may become the source of compassion and acceptance of suffering, which then loses its edge.

Joy from the accomplishments of a handicapped child is possible only when it is fully accepted simply because it is. Instead of dragging the child by force into "normality" one can try to penetrate into its world, to understand the rules of its thinking and feeling. One's own child should not be compared with others, one must reject the norms of height, intelligence quotient. In inner space time does not exist — only love matters.

Ex nostris

Children with Down syndrome can count more on the favor of people around them than children with other handicaps. When in a group of handicapped children I see the characteristic Down syndrome "mask," I feel safer. At home we say of them "*ex nostris*" ("from ours"). In this discrete way the Jews during the occupation spoke of „their own". This is not an entirely innocent jest. Is it not so that the handicapped hide themselves in the society of normal people as the Jews once did, furtively slipping through life?

The common opinion of Down syndrome children is that they are "teddy bears with a small mind" but with a big heart. There is some truth in this. In their families "Downies" as a rule are "specialists in feelings." Their role consists not only in giving love, but also in preserving harmony, easing tensions and strengthening bonds. These children are not fascinated by the world of things, but above all perceive people. Cecylia is a real expert in this respect. She often "philosophizes" on the subject of interpersonal relations. When she understood the relation "the same"/"other," she said of herself her sister and us: "the same." Her empathic attention extends not only to household members. At the sight of a neighbor's prematurely born child, as tiny as a doll, Cecylka cried out gravely: "I love, I love, poor!" This was the first time we had heard her utter such strong words.

Children with Down syndrome not only have the gift of fellow-feeling but also the gift of joy and expression. They watch films with their entire body, talk with the heroes, want to help them. In church — they dance, follow the gestures of the liturgy. Cecylka called the church "Father" for short (from "in the name of the Father and Son"), but she is somewhat afraid of this "Father" even though she knows that He "loves" her. She pronounces theological sentences like: "God loves all dogs." She has one recipe for all the evil of the world, for all sorrows and cares, one happy end: to return "home, to mother." That is how she creates her own little private theology.

When Cecylka was six months old, a baby boy with Down's syndrome was born in the family of our friends. Our friend asked us if one can be proud of a handicapped child and if one can still experience happiness. Yes, one can be proud and happy — we answered in concert. Today Cecylka is seven years old and is attending pre-school, where she is preparing for an integrated school. She already reads simple words. She is an independent and creative person, full of energy, joy of life and good will. We often forget that she has Down syndrome.

Italy or Holland?

Action on behalf of the social acceptance of handicapped persons usually requires some sanction — religious, philosophical or simply moral. In the Polish monthly *Światło i Cienie* (*Light and Darkness*) the problems of the handicapped are presented in the light of the Christian faith. The evangelical attitudes towards them is even close to non-religious people.

Anglo-Saxon bulletins devoted to "Downies"-are of a different nature, more pragmatic. In America the accent falls on "I can." Only "successful people" are shown there — persons with Down syndrome who attend secondary schools, appear on the stage and screen, break sports records, get a driver's license(!). A book recently appeared in the USA that contains talks of adolescent boys with Down syndrome. They speak about everything: about school, sex and marriage, about politics and their independence. J. Kingsley, M. Levitz, *Count Us In. Growing up with Down Syndrome.*

The *Down Syndrome Association News*, published in London, shows not only examples of success but also the problems faced by parents of seriously handicapped children. It turns out that the attitude of compete and unconditional acceptance is also possible without a clear religious or any other sanction. The life of these people is presented without any embellishments, and despite this there is no doubt that this life has exactly the same value as the life of children with "all the necessary qualities." In Great Britain persons with Down syndrome can feel full-fledged members of society without anyone's favor. They do not have to "enrich" anyone or make spectacular progress. This quarterly also presents a mature attitude towards death, thereby transcending a taboo. The publication contains profiles of children who have died (most often from a heart defect). the parents or friends write up a painstaking and creative short biography of the little child, most often ending with the words: "We are proud of him." Some parents who have lost a child with Down syndrome adopt another handicapped child.

The transcending of a taboo can also be seen in the letters of parents, who admit to negative feelings and even to wanting to reject their own child with Down syndrome right after it was born. Such confessions [illegible]ve the value of auto-therapies and are also a help to others. In our country the "shadows" are most often brightened or omitted. Meanwhile, it is first necessary to see the negative emotions in oneself and to call them by name before one can overcome them. The adjective "devastating" is often repeated in the testimonials of parents. "We were devastated" — the readers write — "This was an experience of absolute despair. Tears of joy turned into tears of despair. It is true what people say, that our life can be changed in a fraction of a second;" "I simply wanted to run away from the hospital and leave the child there;" "I cursed fate and hated my child. I wanted it to die." Another mother told how she was ashamed to go our for a walk with her little daughter who had Down syndrome and covered up the child's face with a hood.

Today the authors of these terrible sentences are caring, loving mothers, and not a few of them are simply proud of their child, despite the fact that its mental handicap is a fact. How did they manage to overcome the trap of the feeling of injury and aggression towards their own child? How is it that in time a handicapped child becomes a "comfort," "treasure," "sunshine"?

It is hard for the mother of a new-born child to imagine the way to acceptance of a handicapped child and the possibility of experiencing happiness together. In Poland mothers have to suppress negative feelings. They are often ashamed to speak about them even to their near and dear ones. Meanwhile, negative emotions must first be recognized in oneself and brought to the surface of consciousness so that they can be overcome. The often encountered defense mechanism of the psyche in the first period is an escape into unreality, usually expressing itself in feverish but unfruitful activity, e.g. searching for a miraculous drug or a wonder-worker or escaping into passivity and depression. The author of *Blessings* gives this advice to readers:

I believe that it is possible to identify the point of no re-

> turn, when continuing to feel sorry for oneself becomes a fatal illness that eats us up from inside [...] Self-pity becomes a cancer that starts to destroy the tissue of our courage, then spreads to our humanity and finally masters our capacity to love. [...] Thus if we see ourselves as wronged by terrible fate, every one of our actions will only be filled with sorrow, bitter envy and consciousness of having been wronged. [...] When we try to escape from reality, we only escape from ourselves, thereby throwing away the chance for full participation in society (pp. 175–176).

If we succeed in mastering the pain and do not escape from reality and stop feeling sorry for ourselves, it turns out that life is still beautiful, maybe even more beautiful. Readers of the English bulletin were moved recently by the discussion around the film "Woman of the Year," which is also known in Poland. The hero is a talented boy with Down syndrome, brought up by an ambitious mother, who in the last part of the film expresses her feeling of disappointment and pain, which "will never be soothed, never, never." This disappointment is compared to an "unexpected trip to Holland," which had to take the place of the longed for trip to Italy. "I know that I will never go to Italy — I have to be content with Holland." Readers of the journal protested against this generalization. They wrote that their attitude toward their child does not have even a shade of disappointment or pain. We just — "live the days of our lives," as in the well-known American serial of that title, in which a teenager with Down syndrome appears, the famous Corky. In England 90% of the parents of teenagers with Down syndrome are pleased with them. Would the percentage of satisfied parents of "ordinary" teenagers be as high?

I Don't Try, I Live!

The attitude of our society towards handicapped persons is ambivalent, stretching between two extremes: Christian readiness to bring help and soulless pushing to the margin. The mother of a healthy child in an integrated class admitted that the sight of children in wheelchairs had a "stressful" effect on her and other children. It would be best if the handicapped were not visible in public places. In a park an excursion from an integrated pre-school came upon a festivity connected with a literary competition. One of the by-standers asked the question: "Who brought such children here?"

The mothers of children with Down syndrome know many kinds of aversion and rejection, some of which are expressed in vulgar comments but others in subtle admonishments: "Why didn't you have tests done?" Such rhetorical questions may be heard in the doctor's office even when the child is the picture of health and the joy of the parents, who hardly seek consolation. The parents of not fully able children time and again long for compassion and recognition, but they reject concern combined with negation of the value of their child's life. I still don't like compliments that Cecylka doesn't look at all like a child with Down syndrome. And what would they say if she did? I remember the "letter of sympathy" from a reader of some women's magazine about "slobbering creatures with Down syndrome and their distressed mothers." I personally have not experienced such aversion. Besides, it isn't worth paying attention to the reactions of persons around us, but rather one should impose on others an unconstrained and friendly attitude towards one's child. This is not hard because every day mothers of "children with Down" do not think of them as handicapped or "not fully able" but as Annie or Kate.

The problem of a "sad birth" concerns not only handicapped children. It happens whenever the child is regarded as a commodity that should not have a single defect. In one of the Warsaw hospitals a mother did not want to accept one of her twins because she had only "ordered" one item! Sometimes the reason for rejection if the wrong sex of the child. In the past daughters were a cause of disappointment, but today it varies. *Kobieta i Życie* (*Woman and Life*) printed a letter from a reader who was embittered because instead of the daughter she wanted she had given birth to a son. I remember the terrible sentence from her letter: "My husband and I are pleased only when the little one is asleep and we can quietly watch television." In the letter the little boy was even deprived of his name. As Jean Vanier wrote, "*The real misfortune is not lameness, but the absence of love.*"

Psychologists say that children with Down syndrome stand a greater chance of being rejected by parents with higher education. Hanna Olechnowicz in her book *Portraits of Handicapped Children and Recommendations for Upbringing and Therapy* (Warsaw 1991) gives examples of children with Down syndrome trained by mothers in reading and counting, forced to copy thoughtlessly signs which are incomprehensible to them. These are also examples of the silent martyrdom of children who are rejected and punished for who they are.

The best educational solution seems to be integration — starting from elementary school, through schools and clubs, There are a lot of programs on television devoted to the not fully able. It is a pity, however, that there is no practice of inviting handicapped children to participate in ordinary "telemornings" and "good-night shows," without making a special comment about this — such children could appear as "normal" children, playing together with other ones.

The great worry of parents of children with Down syndrome is the fact that one day the children will be left alone. They want to create for their children the prospective of a life that is simultaneously protected and independent. In the program from the series "Shalom" Michał Nekanda-Trepka showed an Israeli film about a kibbutz of handicapped people who have their own self-management board composed of themselves. Before the film there was a discussion with Ms. Joanna Garlicka, a person with Down syndrome who has been living independently since the death of her parents. To the words of the reporter: "You are trying to live independently!" — Joanna Garlicka replied emphatically: "I'm not trying to live, I am living!"

Masks

In the world of fiction — films and novels — we accept oddballs, queer customers and monsters. It is not so in life. Rabbi Kushner and Mary Craig had to struggle with the hardest task - bringing up a child with a repulsive appearance. Mary Craig confessed that as the happy mother of a healthy child she herself avoided contact with handicapped children. Then a familiar doctor said of her second son: "That's an animal."

Why do we get out of our depth when we come into contact with lameness or abnormality? Handicapped persons disturb our peace, intrusively remind us of our own limitations and our mortality. We cannot forgive them for that. We are afraid of being infected by misfortune. We mask our fear with aggression.

"*God does not have His own face. Every human face is the face of God*" — professes the Indian sage Swami Muktananda, who surely did not know Levinas. A human face is the Epiphany of God! It is easy to see God in small, delightful children, in animals and in nature or in our dear departed ones. However, it is the hardest to see Him in faces deformed by a handicap. Theologians often equate handicapped persons with "the poor in spirit," with the blessed in the Sermon on the Mount, who keep nothing for themselves, who give everything away. They are transparency itself. Their existence may be the space for the divine light to shine through.

A handicapped person is a living sign. The infirmity of the human body points to something more important beyond it, where perhaps the secret of our humanity is concealed. Lameness enables us to understand that our corporeality is transparent. Maybe not only our body but also our personality, our rational consciousness is only a mask? And maybe that is why it is easier to see the divine light in the eyes and smile of a handicapped child? Contrary to appearances, this is not awareness of the slight value of the body, but joyful knowledge, enabling us to accept limitations with a proper degree of aloofness, even humor.

Lameness or monstrosity may seem to be only a mascarade, a costume veiling the sheen of perfection. That is why we love Fellini's monsters — people who are monstrous. fat, dwarfish. The heroes of Lasse Hallström's film "What's Eating Gilbert Grape?" are a terribly fat mother and her mentally handicapped son, who is called "Sunshine." In the films of Fellini and Hallström dissimilarity and lameness are not treated with pity (often concealing aloofness and abhorrence) but with all-embracing humor, which is the sign of love.

Accepting their deformity, we feel safer in a world in which what is human has an infinite number of forms. We sometimes admire the beauty of tired out faces of old people. The faces of old actors loose nothing; on the contrary, they become the sign of immutability, duration. The actor passes from the role of a lover to the role of a senior. Meanwhile, we, in life, sometimes cling to one role, playing it without talent and also for too long. The problem of old-age, as the experience of divesting oneself of one's own body, was described with great precision, not without self-irony, by Maria Kuncewiczowa in *Slides*: "*I am eighty-odd years old. My partner for sixty years told me yesterday: 'I like to look at you' — he was so moved that he doesn't see me galloping on a broomstick. But what a daily burden it is: 'to look good.'*" In these ruminations there is not only bitterness over the loss of youth. There is also joy from the unexpectedly regained "nakedness," that is, internal freedom, in old-age.

At first glance the photographs of Diane Arbus showing the inmates of institutions for the mentally handicapped fill us with sorrow. But after we have become accustomed to the sight of these queer, deformed figures, we begin to see the light in their eyes, and their smiles become genuine. What is interesting is that Diane Arbus gave her models carnival masks and costumes, putting the mark of clownery on their lameness. One can see in this gesture derision or the deepest solidarity, community of human fate in the carnival circle of existence, where we all wear masks. The inmates of a social care institution become "jesters of God," after the fashion of Saint Francis.

In associating with very old or handicapped persons — we enter the sphere of silence. Handicapped persons elicit not pity but rather a certain kind of emotion, which sends us deep into ourselves, to a place where there is no longer any compulsion or any fear. Through the mediation of these persons we can touch the very core of our humanity, which does not depend on how well our body and mind work. A crippled body, an enfeebled mind betoken — in a paradoxical way — the perfection of these people. And of all people. Looking at handicapped persons in this way, we can see in them not "others" — but ourselves.